

Legal and Ethical Issues Regarding End-of-Life Care in Korea*

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Korea legislated withdrawing or withholding life-sustaining treatment after the Korean Supreme Court Decision on Grandma Kim's Case. However, the Proposal for Legislation by the Korean National Bioethics Committee and the Supreme Court decision have some limitations. Both limits the patient's ability to decide to withdraw or withhold life-sustaining treatment to cases involving a dying patient who is about to die. The Hospice and Life-sustaining Treatment Act also reflected this limitation. Only POLST signed by competent patients themselves is fully respected as a patient's wishes. The Supreme Court decision reveals theoretical confusion between the principle of respecting autonomy and that of a patient's best interest. Even though the Proposal and the Act outline certain procedures for surrogate decision-making, they may be problematic in that they place a heavy weight on family members' decision making. This limitation should be overcome with ethical, legal, and sociological studies. Despite this limitation, any legislation based on the Proposal was needed in Korea. Building a medical system with better palliative care or hospice care should be emphasized to prevent the abuse of withdrawal of life-sustaining treatment. The values of familism should be balanced with those of autonomy.

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Introduction

Legislation regarding withdrawing or withholding life-sustaining treatment has been a controversial issue in Korea. The Congress passed the Hospice-Palliative Care and Decision on Life-sustaining Treatment Care of Dying Patients Act (hereinafter referred to as 'the Act' or 'the Hospice and Life-sustaining Treatment Act') this February. The Boramae Hospital case made physicians worry about being convicted of murder even though this case should be considered to be a case of discharge against medical advice. Grandma Kim's case prompted a wrong response from physicians. The Korean Supreme Court decision on Grandma Kim's Case is the first case to deal with the genuine bioethical issues relevant to life-sustaining treatment in Korea. After the decision, the Korean National Bioethics Committee presented its Proposal for Legislation on Life-sustaining Treatment. The Proposal has legal and social significance in that it suggests a basic framework for such legislation while considering the main contents of the Decision and trying to reflect various voices.

However, the decision and the Proposal also have some fundamental limitations, which affected the Act. Critical review of the decision and the Proposal will contribute to the development of the future agenda for bioethical issues in Korea. After I deal with these limitations, I emphasize the need to balance the values of autonomy and those of familism and suggest a need for more empirical studies on bioethical issues related to autonomy and surrogate decision-making.

Grandma Kim's Case

The legal case of Grandma Kim vs. Severance Hospital is the first one to deal with withdrawal of life-sustaining treatment in Korea from bioethical perspectives. Some may say that the Boramae Hospital case is the first legal case to deal with withholding or withdrawing life-sustaining treatment. Even though the case has prompted Korean medical practitioners to behave very conservatively due to the fear that physicians will be charged with murder, it does not have any meaningful bioethical implications since it involves a type of discharge against medical advice. Clearly it was ethically wrong to withdraw life-sustaining treatment for the patient in the Boramae Hospital case. The patient himself did not have any wishes to withhold or withdraw his

life-sustaining treatment. His surrogate decision maker, his wife, did not have any intention to act in his best interest. The attending physician did not think that the life-sustaining treatment was medically futile.

Grandma Kim's case is similar to Karen Quinlan's case. Grandma Kim, a 77-year-old, was incompetent. Her mouth and nose were clogged with a ventilator and feeding tube (after excessive bleeding caused by a botched endoscopy operation). Her family members requested Severance Hospital to remove the ventilator (not the feeding tube) on her behalf.

Supreme Court Decision

The Supreme Court upheld an appellate court ruling that allowed the removal of the ventilator from the patient, who was dying and had little chance of living. We have to pay attention to some important points from the Supreme Court Decision (2009DA17417). First, the Supreme Court theoretically declared a patient's right to self-determination regarding treatments in general. But it was also emphasized that when a treatment is directly related to a patient's life (that is, death), the decision to stop the treatment must be decided *very carefully* under *very restricted* circumstances.

Second, the Supreme Court decision provides general guidelines for withholding or withdrawing life-sustaining treatment. For life-sustaining devices to be removed, the following four conditions must be met; 1) Dying patient; with no possibility of recovering consciousness; no possibility of recovering his/her important physical functions related to life; it is clear that he or she will die soon; treatment (life-sustaining treatment) does not aim to improve the condition, but aims to keep the current condition. In this situation, treatment is considered to artificially delay the end period in the process toward death.

2) Patient's self-determination; a patient's right to self-determination may be considered to be exercised when a Letter of Advance Medical Intent (like AD in the U.S.A except for Durable Power of Attorney, thus similar to a living will) was made with a physician after a competent patient obtains sufficient information from a physician. (If a LAMI was not made under the above conditions, it is merely a kind of objective evidence that may be used to estimate a patient's wishes.).

3) **For dying patients without LAMI**; a patient's wishes can be objectively estimated with objective evidence including a patient's expression to family members and friends, his/her reactions to treatments for other patients, his/her religion and way of life, and his/her medical condition, etc.

4) **Committee's judgment**; it is desirable that a committee consisting of specialists decides whether a patient is a dying patient with no possibility of recovery if a patient or his/her family does not appeal to court for the decision.

With regards to the conditions above, Grandma Kim's case belongs to the category, "dying patients without a living will" (#3 in the list above). The removal of Grandma Kim's ventilator was based on the following reasons. The decision says:

It is reasonable and in accordance with social norms that we accept that we can presume a patient's wish to stop life-sustaining treatment when the patient might be considered to choose to stop life-sustaining treatment if a chance for the exercise of *the right to self-determination* were given to the patient because stopping life-sustaining treatment is considered to objectively be in *the patient's best interest* in terms of the patient's values or beliefs."(My italics)

Comments on the Reasons of the Decision and Its Implications

In the section of the decision quoted above, the "right to self-determination" (that is, "autonomy") and the patient's "best interest" are seemingly conflated. This means that the principle of respect for autonomy and that of best interest are mixed up.

The principle of respect for autonomy is involved in the phrase, "when the patient might be considered to choose to stop life-sustaining treatment if a chance for the exercise of the right to self-determination were given to the patient." And the principle of best interest is involved in the phrase, "stopping life-sustaining treatment is considered to objectively fit to the patient's best interest in terms of the patient's values or beliefs."

How do we have to interpret the decision's appeal to the two principles? The logical structure of the decision should be interpreted in accordance with the "substituted judgment" standard (Choe & Kim 2009, p. 167). The appeal to the principle of respecting autonomy implies that we may accept a patient's decision although it may not quite be in his/her best interest from a medical perspective. If we did not interpret the decision to follow the "substituted judgment" standard, the decision might sound absurd because it appeals to the two, often conflicting, principles.

According to Tom L. Beauchamp and James F. Childress, there are three standards for surrogate decision making; 1) the substituted judgment

standard, 2) the pure autonomy standard, and 3) the best interests standard (Beauchamp & Childress 2013, pp. 226-9). However, the first standard has a serious problem in that it cannot apply to a person who has never been competent. More importantly, when we seriously consider the substituted judgment standard, we must ultimately reach either the pure autonomy standard or the best interest standard. For the basic premise of the substituted judgment standard rests on a fiction (Beauchamp & Childress 2009, p. 136).

Thus, we should follow the pure autonomy standard when we try to estimate a patient's wishes. Beauchamp and Childress say, "The pure autonomy standard applies exclusively to formerly autonomous, now-incompetent patients who expressed a relevant, autonomous treatment preference." They continue to say, "The principle of respect for autonomy compels us to respect such preferences" (Beauchamp & Childress 2013, pp. 227-8). This suggests that respecting a patient's preferences depends on how much the principle of respect for autonomy prevails in a specific society. In addition, the acceptance of the pure autonomy standard presupposes that we have to know a patient's wish. As Beauchamp and Childress say, "This standard asserts that, whether or not a formal advance directive exists, caretakers should act on the patient's prior autonomous judgments, sometimes called 'precedent autonomy'" (Beauchamp & Childress 2013, p. 228). In this respect, it is reasonable that objective evidence is requested in order to ascertain a patient's prior autonomous judgments.

What do we have to do if we do not know or cannot estimate a patient's wishes on the basis of objective evidence? In this circumstance, we should follow the best interests standard. Beauchamp and Childress say, "If the previously competent person left no reliable traces of his or her preferences - or if the individual was never competent - surrogate decision makers should adhere to the best interests standard" (Beauchamp & Childress 2013, p. 229). They also say, "Under the best interests standard, a surrogate decision maker must then determine the highest probable net benefit among the available options, assigning different weights to interest the patient has in each option balanced against their inherent risks, burdens, or costs" (Beauchamp & Childress 2013, p. 228).

Finally, the Supreme Court decision does not provide reasons that quite adhere to theoretical standards for surrogate decision making. Its stated reasons reveal the misuse of the relevant terms. The use of "right to self-determination" is not proper because the actual reason of the decision is based on the patient's best interest. One may argue that the use of "right to self-determination" can be considered to follow the substituted judgment

standard. However, the substituted judgment standard has to consider a patient's hypothetical decision under a given situation guessing the patient's wishes rather than the best interest of the patient. The Court's discussion of "*the patient's best interest* in terms of the patient's values or beliefs" also reveals that the Court does not properly use the term "best interest" (Choi 2014, p. 243).

In addition, the decision has the following limitations. First, the Supreme Court limited the removal of life-sustaining treatment to dying patients who will die soon because it considers life-sustaining treatments applied to dying patients to artificially delay the end period in the process toward death. We have to allow for the fact that Korea does not have any regulations to legally assure a patient's refusal of medical treatment whereas the U.S.A. has the Patient's Self-determination Act to assure the right.

Second, the Supreme Court limits the power of LAMI (i.e. living wills) made without a physician. According to the Court's decision, a LAMI made without a physician is merely one kind of objective evidence to identify or estimate a patient's wish. Generally, living will is this kind of LAMI unlike POLST (Physician Orders for Life-Sustaining Treatment). Thus, we can conclude that LAMI made without a physician, that is, living wills in general cannot be legally considered to be the exercise of the right to self-determination. What legal power living wills as a form of objective evidence may have is likely to depend on how strongly Korean society intends to respect a patient's wishes. I wonder if Korean society will fully respect a patient's wishes. The mixture of the principles discussed above and the misuse of the terms relevant to surrogate decision making both indicate that Korean society and the Supreme Court are not ready to fully accept a patient's refusal of treatment. This is also apparent when we compare the Supreme Court's reasons for its decision with the Supreme Court of Missouri's reasons in Nancy Cruzan's case. The Supreme Court of Missouri says;

We assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition. . . . Missouri has in effect recognized that under certain circumstances a surrogate may act for the patient in electing to have hydration and nutrition withdrawn in such a way as to cause death, but it has established a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent. Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be proved by clear and convincing evidence (Shepherd 2009, p. 741.).

The Court's acknowledgement of the right to refuse treatment including even hydration and nutrition is noteworthy, as is the emphasis on clear and convincing evidence of an incompetent patient's wishes in the case of surrogate decision making rather than any mention of "a patient's best interest."

Proposal for Legislation by National Bioethics Committee in Korea

The Proposal for Legislation

The National Bioethics Committee in Korea put forward the Proposal for Legislation on Life-Sustaining Treatment in July 2013. The Proposal is as follows. First, the Proposal limits the condition of a patient who is eligible for withdrawing or withholding life-sustaining treatment as a dying patient;

- 1) with no possibility of recuperating;
- 2) who is not reactive to treatment for his/her disease;
- 3) who deteriorates rapidly.

Second, the treatments that are subject to the decision to withdraw or withhold are special life-sustaining kinds of medicine (so called "extraordinary treatment" such as CPR; ventilator; hemodialysis; anticancer drugs, etc.). Ordinary treatments such as feeding tubes, palliative care, etc. are excluded according to the first version of the Proposal, although the final Proposal does not clearly mention what ordinary treatments are.

Third, the frame of decision making is as follows: 1) Clear and current wishes from a patient should be respected. A Plan for Life-sustaining Treatment made with an attending physician after the patient is informed of current or soon to occur conditions and can make a rational decision is recommended. In addition, a Letter of Advance Medical Intent made with an attending physician is accepted as a patient's clear and current wishes.

2) When there are no clear and current wishes from a patient, a patient's wishes can be estimated in the following ways. A Letter of Advance Medical Intent made without physicians can be treated and accepted as a patient's wishes after two physicians (one attending physician and one expert physician) review this LAMI. Alternatively, concordant statements from more than two family members can be treated and accepted as a patient's

wishes after two physicians (one attending physician and one expert physician) review these statements.

3) When there are no clear and current wishes from a patient and no possibilities to estimate a patient's wishes, the following procedures can be taken after two physicians conduct a review:

i) a legally appropriate attorney can make the best decision for the patient, ii) all members of the family (spouse, descendants, and ascendants only) can make the best decision for the patient, iii) the hospital ethics committee can make the best decision for the patient when there are no family members.

Comments on the Proposal

The Proposal had great significance for Korean society in that it proposed a framework for any legislation on life-sustaining treatment. In addition, the Proposal was significant in that it had been made by an ad hoc committee that included many experts working under the National Bioethics Committee. However, the Proposal still has the following limitations. First, the Proposal focuses only on dying patients who will die soon. A terminally ill patient is outside of the Proposal. This exclusion mirrors the Supreme Court decision regarding Grandma Kim's case. The Act has the same limitation. If patients do not receive hospice care, then the withdrawal or withholding of life-sustaining treatment is applied only to dying patients, not to terminally ill patients.

Second, the Proposal, like the Supreme Court decision, limits the power of a Letter of Advance Medical Intent (LAMI). A LAMI made without a physician may not be fully respected and may be accepted as a patient's wishes after the review of two physicians (one attending physician and one expert physician). The power of such a LAMI is likely to depend on how the LAMI was made. Thus, the Act introduces an organization designated by the Ministry of Health and Welfare. The unit registers and manages Letters of Advance Medical Intent for Life-sustaining Treatment. The Act reflects the consideration of strong opinions against LAMI made without a physician. The Korean Catholic Church has worried about the abuse of LAMI. The Church seriously takes into account the Korean medical context in which national medical insurance does not yet fully cover the financial burden for terminally ill-patients or their family members, including the cost of palliative or hospice care.

Third, the proposal gives great weight to family members when it comes

to surrogate decision making. Family members may have too much power and face conflicts of interest. This phenomenon may be understood to reflect an aspect of Korean culture known as “familism.” Hospitals have conventionally asked family members to make a decision on behalf of a patient. However, there is no clear and sufficient evidence based on survey research to justify this kind of institutionalized respect for familism. According to Kwon et al., 59% of patients surveyed want to designate their spouse as their proxy while 30% of them want their offspring to serve as their proxy and only 5% of them want physicians. But only 20% of patients’ guardians say that they are sufficiently aware of their patient’s view of life, values, and wishes regarding treatment options when faced with an irreversible condition. 60% of patients’ guardians say they are “roughly aware of” these factors, and 12% of them say they are “not aware of” them (Kwon et al. 2010, pp. 7-8). Thus, we still need more sociological studies on whether our respect for familism is valid or not.

Fourth, how two physicians review LAMI, family members’ statements, and a proxy’s decision is not clear. I doubt if physicians are eligible for the above tasks because such a review may go beyond physicians’ abilities. The same procedures are regulated in the Act. Thus, the same question is raised with regards to the Act.

Comments on the Hospice and Life-sustaining Treatment Act

The problems of the Supreme Court decision and the Proposal arise with regards to the Act because the Act was written with those documents in mind. Besides these familiar considerations the Act has a unique problem. The Act does not only deal with the life-sustaining treatment problem, but also with hospice or palliative care for terminally ill patients. The Act is significant in that it expands hospice or palliative care to terminally ill patients beyond cancer patients whereas previously the Management of Cancer Patients Act dealt with palliative care only for cancer patients. But the unique problems of the Hospice and Life-sustaining Treatment Act come from the mixture of the Bill on Life-sustaining Treatment and the Bill to modify the Management of Cancer Patients Act.

First, there is no clear regulation of the relationship between withholding life-sustaining treatment and receiving hospice care. Hospice practices involve the withholding of life-sustaining treatment. But the failure to clearly mention this in the Hospice and Life-sustaining Treatment Act may mislead

citizens and some health care professionals into the idea that withholding life-sustaining treatment must be applied to only dying patients, rather than terminally ill patients who receive hospice care.

Second, the Act has the double standard of surrogate decision making. As with the Management of Cancer Patients Act the Act allows for a system of surrogate decision making, such as durable power of attorney in the case of hospices. This means that a non-family member proxy for a patient receiving hospice care may withhold life-sustaining treatment for a terminally ill patient while only family members may withhold or withdraw life-sustaining treatment for dying patients. A more significant problem is that there are no detailed regulations on how proxies for patients in hospice care will be designated.

Importance of Considering Social and Cultural Context

Although the Proposal and the Supreme Court decision have some limitations, the Act based on the Proposal has a significant meaning for Korean society as the first step towards policies on life-sustaining treatment. The above limitations are expected to be overcome with more accurate ethical, legal, and sociological studies. I argue that any legislation based on the Proposal is better than no legislation. The status quo in medical settings causes lots of problems involving the application of medically futile treatment only because many physicians are worried about being convicted of murder.

Building a Medical System for Palliative Care or Hospices

Before the Act is enforced, however, we have to build a solid medical system for palliative care or hospices. Palliative care is limited in Korea. Hospice or Palliative care is financially supported for cancer patients alone by the Korean National Health Insurance system. Thus, other terminally ill patients are likely to be reluctant to choose hospice care.

To build such a medical system, we must also overcome cultural problems related to end-of-life care. A patient's sons or daughters are inclined to do their best to make their parents survive as long as possible even if they know that life-sustaining treatments are futile. The reason is that they are very sensitive to society's perceptions. In addition, this aspect of Korean culture unfortunately leads the decision to receive hospice care to be regarded as giving up on the hope of treating the patient.

Financial support for hospice care should be extended to all terminally ill patients at the end of their lives. The Hospice and Life-sustaining Treatment Act still has limitations because the Ministry of Health and Welfare should decide the legal scope of terminally ill patients. In addition, an educational program dealing with death as well as end-of-life care including hospice care should be developed. Furthermore, familism and the ideal of an individual's autonomy should also both be critically reviewed from various perspectives including cultural ones. Policy makers should try to rebuild social systems such as the medical insurance system in which individuals may freely pursue their own wishes beyond the mere emphasis on autonomy.

Autonomy and Familism

Respecting autonomy has been one of the most important principles in medical ethics since Beauchamp and Childress wrote their famous monograph, *Principles of Biomedical Ethics* and the Belmont Report was published. The principle of autonomy sometimes seems to dominate solutions for lots of bioethical issues in Eastern societies as well as in Western ones. Recently, new approaches to understanding autonomy have been developed in Western culture. Some suggest a notion of "relational autonomy" that challenges the individualistic fantasy. Some Western and Eastern scholars have emphasized the values of family rather than those of the individual. For example, John Hardwig 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?" (Hardwig 1997) He also argues that a family should make the treatment decision when the lives of family members would be dramatically affected by the treatment decision in his article, "What About the Family" (Hardwig 1990). It is true that historically individual autonomy has been emphasized with the advance of an individualistic society. Autonomy as a value along with free will, however, cannot be devalued when we are considering the foundation of morality, especially modern morality (Choi 2015, p. 83).

Hardwig criticizes the notion of individualistic autonomy. He suggests that family should be seriously considered (Hardwig 1997). I agree with Hardwig's view that an individual has to have responsibility for his/her family members. This kind of discussion may be valuable for the Western societies in which an individual's individualistic free choice has enjoyed the absolute priority. On the other hand most of the elderly in Korea, however, feel a

moral obligation to their offspring. Hardwig's view is not something new in Eastern cultures. When they say they do not want any life-sustaining treatments, Korean seniors are considering the fact that such treatments are likely to waste money that could otherwise be used for the benefit of their offspring. Most Korean people do not have an individualistic fantasy. The reality is in fact the opposite. Koreans may feel the burden of tight relationships among family members. In this respect, Hardwig's point that there are moral obligations to family members may not be salient in Eastern societies which have not yet fully developed the value of autonomy. Family members should participate in the process of decision-making for life-sustaining treatment and hospice care, etc., not in decision-making in itself. The decision of family members is not the same as that of an individual person. The latter cannot be reduced to the former (Choi 2015, p. 86-7).

When we do not know what wishes an individual has even though we have to decide on behalf of an incompetent patient, we may accept the standard of best interest for a patient. We have to note that conflicts of interest may be involved in a decision when a family decides instead of an individual because family members have in most cases a burden to pay medical fees (Choi 2015, p. 86-7).

Conclusion

A competent patient should appreciate the value of family and take into account the family member's values and needs. But the final decision should be made by an individual if he/she is competent (Choi 2015, p. 88). The patient's family members cannot replace the patient's own right to self-determination, which has been developed over the course of modernity. If the patient is not competent and we know or estimate his/her wishes on the basis of objective evidence, we should respect the patient's wishes. In this situation, we follow the standard of pure autonomy that Beauchamp and Childress mention (Beauchamp & Childress 2013, pp. 226-9). The Proposal and Hospice and Life-sustaining Treatment Act consider concordant statements from more than two family members as a patient's wishes as long as there is no objective evidence to override these statements. This is a very unique approach to objective evidence to reveal a patient's wishes. Provisionally, I accept this approach as a proper one to reflect Korean culture. But we need a future empirical study on whether this approach is being abused or not.

If the patient is not competent and we do not know his/her wishes, the

standard of best interest should be accepted as Beauchamp and Childress mention (Beauchamp & Childress 2013, pp. 226-9). In this situation, family members may participate in the decision-making. The Proposal and The Act let all members of the family (spouse, descendants, and ascendants only) make a decision on behalf of the patient. But family members' decision must be made on the basis of the best interest of the patient with special consideration of the potential for conflicts of interest. In this respect, the two physicians' review of the family members' decision is important. Although the Act does not clearly mention what the two physicians should pay attention to, it is very clear from a theoretical perspective that they must review whether the decision all members of the family made fits together with the best interest of the patient.

Finally, I emphasize the idea that the value of an individual and that of his/her family should be balanced. If the value of family is relatively underestimated, we have to emphasize its importance like Hardwig. If the value of an individual is relatively underestimated like in Korean society, we have to balance this value with an emphasis on autonomy. In Eastern cultures, especially Korean culture, autonomy is still an important value that needs to be developed over the coming years (Choi 2015, p. 90). Korea cannot deny the value of autonomy that has developed over the course of modernity. The Supreme Court decision, the Proposal, and the Hospice and Life-sustaining Treatment Act do not ignore the value of self-determination. Thus, the success of the Act will depend on how many terminally ill patients make POLST with their physicians when they are competent.

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