Caring from the Phenomenological Point of View
--- Decision-making in terminal care in Japan

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Introduction

Suppose here was a dying patient in the terminal stage. First, imagine that the patient was me. In what kind of world would I, approaching my end, still be living, and what kind of care could I hope for from my family, my friends, and medical personnel? Secondly, imagine that the patient was a member of my family or my best friend. In what kind of world would I be living, and how would I be attending him or her as a patient, and what could I do him and her, and what would I hope the medical personnel involved would do? Thirdly, imagine that I was one of the medical staff caring for the patient. In a situation in which there was no possibility for treatment and life was coming to an end, in what kind of world would I be living as a doctor or a nurse? What could I do for the patient and his and her family and friends? As to the impending death, in the first case I would meet “my” death in the first person (of course, it is exactly impossible for me to meet my death); in the second case I would meet “your” death in the second person, and in the third case I would meet “his or her” death in the third person. There are different perspectives from which the situation can be seen. How should we make crucial decisions regarding the patient? How can we investigate such a situation from a phenomenological point of view? This is the subject of this paper.

1. Background: phenomenology and medicine

The relationship between phenomenology and medicine began with psychiatry. In psychiatry, Jaspers, Binswanger, Boss, Brandenburg, and others were interested in the phenomenological philosophy of Husserl, Heidegger, Sartre, Merleau-Ponty, and others, and tried to convert ideas such as phenomenological reduction, essential
intuition, and transcendental functions into methods to approach the world where patients live—not to explain it from the outside, but to understand it from the inside. This so-called “psychopathology” was introduced and developed mainly by Bin Kimura in Japan. It prospered in the 1970s and 1980s under the name of phenomenological or anthropological psychiatry. But recently, with schizophrenia, the main object of their research, decreasing and becoming milder, it is said that the time of psychopathology is reaching its end. In its place, the biological psychiatry making full use of gene research, brain image mapping, and epidemiological statistical research has become pervasive in psychiatry. The influential power of phenomenology in psychiatry seems to have been lost.

Such a change is not limited to psychiatry. Medicine has had a tendency to become almost a biomedical natural science since the 19th century. Nevertheless, in the 20th century, especially after World War II, as natural-scientific medicine showed both its positive and negative sides, problems of medical ethics and bioethics were discussed. Now, even if the word “phenomenology” itself is not used, phenomenological thoughts are pervasive in medicine, though more so in medical care than in medical science—that is, more so in patient-oriented medicine than the traditional doctor-oriented medicine. On the one hand, phenomenology is linked to the assertion of “patient's rights,” or the change from “paternalism” to “informed consent” discussed in bioethics, and on the other, it is linked to the distinction between “disease” and “illness” argued in medical anthropology.1

From a phenomenological point-of-view, the shift toward patient-oriented medicine could be considered a conversion from a medicine treating “disease” as an objective state that can be explained by medicine as natural science, to a medicine treating “illness” as a subjective meaning for the patient in his/her living world. It reminds us of Husserl's phenomenology, which insists that the sciences, seeking objectivity, forgot the foundation of their studies, i.e. the “life-world,” in which they were originally rooted, and that the sciences fell into a crisis, and that for the sciences to be saved, all scientific knowledge needs to be “put in parentheses” and scientists must

return to the life-world as the place of original evidence, and found science newly once more. We must come back from the natural-scientific biological medicine seeking objectivity and universality to the patient's life-world, and discover a medicine grounded in the life-world.

Although the main stream of medicine, as medical science, still emphasizes “EBM (Evidence-Based-Medicine),” which gives priority to empirical data (evidence) about patients' bodies, there is also an “NBM (Narrative-Based-Medicine)” movement emphasizing the narratives of patients themselves. This movement is connected with the narrative approach or the narrative therapy that has been becoming prominent in sociology. If we go back to both their origins, we can find the stream of phenomenological sociology founded by Alfred Schutz, a student of the later Husserl, who fled the Nazis and obtained political asylum in the United States during World War II. Although the term phenomenology isn't used anymore, and the narrative, as part of a social constructivism stressing language, seems something separate from phenomenology, the spirit of phenomenology is still alive in the method of letting a patient's life-world emerge from his narrative. This “NBM” movement emphasizing patients' narratives is now entering into psychiatry too, where medical examination by interview as oral therapy (mündliche Therapie) has been highly valued. It could be regarded as a renaissance of phenomenology in psychiatry.

I mentioned above that the relationship with phenomenology is found more in medical care than in medical science. An interest in phenomenology developed in nursing care soon after that in psychiatry. Nowadays the influence of “EBM” is strong also in nursing studies, but phenomenological studies in nursing continue to be carried out as qualitative research rather than quantitative research, under the name of hermeneutic phenomenology or the phenomenological approach. Among such studies in nursing, I would like to mention only one—an outstanding study of Yumi Nishimura's: *Talking Body—Phenomenology of Nursing Care.* Corresponding to

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phenomenological studies on the part of researchers in nursing, there is a developing interest in nursing care on the part of researchers in philosophy. In this paper, I would like to discuss the phenomenology of care in a wider sense than just nursing care.

2. Phenomenological anthropology of Caring

In phenomenological terminology, caring in the widest sense is a kind of intentionality of consciousness, namely intentionality which functions more in the dimension of action than in the dimension of cognition, as well as intentionality which is not closed within the self but relates to the other. If care directed toward the other does not lead to his or her satisfaction, by no means can it be considered care in the true sense—even if it leads to self-satisfaction. Insufficient care becomes no more than a small kindness, and excessive care becomes only an inappropriate effort. Neither one nor the other becomes adequate care. There is always a possibility of discrepancy in giving care and receiving care.

As is often introduced in books dealing with the subject of care, Martin Heidegger in *Being and Time* characterizes the fundamental way of human being as “caring (Sorge),” and also characterizes it as “Being-in-the-World (In-der-Welt-Sein),” as well as “Together-Being (Mitdasein).” Care means that we are always in the world and relating to the other. More exactly, we can say that I refer to the other, and at the same time the other refers to me, that we live in relationships of “caring and being cared for.” Caring requires relationships between human beings, or in Husserl’s terminology, an intersubjective way of being in the “life-world (Lebenswelt),” or in Bernhard Waldenfels’ or Bin Kimura’s terminology, the phenomenon of “between (Zwischen)” between persons.

However, this does not imply a homogenized community of “us.” The

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5 Shinji Hamauzu: *Husserl’s Phenomenology of Intersubjectivity* (Japanese), Sobunsha, Tokyo, 1995.
6 If I can make a remark about the use of the expression “phenomenological anthropology,” Husserl sketched several ways to the transcendental phenomenology, one of which was “phenomenological psychology.” Studies on the same dimension should be “phenomenological sociology” and “phenomenological anthropology,” a trial of which is the theme of this paper.
intersubjective world phenomenologically understood is a multi-perspective world with views spreading out radially from the zero of “Now-Here-I.” It is a non-homogeneous world that constitutes itself from an exchange of standpoints and communication between this “me” and “others” holding different perspectives. While the word perspective was originally used in a spatial sense, Husserl used it also in a temporal sense; however, we can also use it in a personal sense. The multi-perspective world signifies the world which includes spatially top and bottom, right and left, front and rear, far and near, temporally past, present, and future, (temporally) far and near, and personally the differences originating from interaction among the first, the second, and the third person.

To consider the theme of “caring” phenomenologically, we must take the relationships among human beings and the personal nature of the relationships into consideration. When we are born, as well as when we die, we always do so among such relationships and personal perspectives. Birth as well as death, namely if I may speak from a Buddhist point-of-view, birth, aging, illness, and death (shiku 四苦), are events in relationships or in the between (Zwischen) and with personal differences. Arthur Kleinman distinguished between “disease” as an object of objective medicine and “illness” as a lived subjective experience in his work The Illness Narratives. In this work, we can find the differentiation between a “disease” grasped in the third person and an “illness” lived in the first person. Vladimir Jankélévitch made a distinction between death in the first person, the second person, and the third person in La mort,7 and here we can also find a phenomenological consideration in the background. When considering the Buddhist ku (“suffering”) involved in “birth, aging, illness and death,” we can designate the suffering person as the first person, someone speaking with you to the first person as the second person, and people surrounding both persons at a distance and providing care as the third person.

Similarly, personal differences come into play in medical treatment. Above all, in terminal care, it becomes an important issue. The difference of person is also to be substituted with a question who the person concerned is. In medical scenes it is the patient who suffers in the face of death in the first person. If illness or death is an

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event in a relationship, we can also call his or her family or friends (i.e. those who call
him you) one of the persons concerned. Furthermore, we can say that medical
personnel who treat terminal illness are participants in the event, third-person
participants. (If criminal “euthanasia” occurs, the medical staff involved becomes
connected to the crime.)

As differences in person and perspective play a big role also in medical situations,
there is a need for those involved to integrate the differences through communication
with each other. In reality, the communication does not always succeed; it is often the
case that divisions remain and opinions conflict. In those cases, it is
important—speaking from a phenomenological point of view—that this difference of
person has an order of precedence. It is the suffering and dying patient in the first
person who is the most fundamental and important. Of secondary importance is the
person who stands in the “you”-relation with the patient. And last, but whom we must
not ignore, are the medical personnel who make efforts to rescue the patient and
accompany him or her. In order not to lose from sight such a precedence order, we need
to communicate with each other, paying mutual attention to each point of view.

Such a consideration overlaps with problems of bioethics. In bioethics, one
discusses, on the one hand, problems involving legal issues of rights, duty, and justice;
and on the other hand, problems in care such as a patient’s QOL (quality of life) or “cure
and care.” The discussion of what should be the basis of ethics—that is, whether
justice and rights should be the basis of ethics or caring and responsibility, is also dealt
with in bioethics. Next, I would like to consider the contrast between the “ethics of
justice” and the “ethics of care” from a “phenomenological point of view of caring.” But
owing to limited space, I would like to hurry to one concrete problem of care—terminal
care.

3. On terminal care in Japan

8 We have no custom to use the word you to address each other. A family does not always have an
intimate relationship in the second person.
9 From “Anthropology of Care” cf. Shinji Hamauzu (ed.): Introduction to the Anthropology of Care,
Chisen-shokan, Tokyo, 2005.
In March of the last year, incidents in a municipal hospital in Toyama Prefecture were reported in the media almost every day for several months. Seven patients in terminal stage by cancer or so were removed from their artificial respirators. I would like to mention here the following three points from the information reported: First, there seemed to be a silent, unwritten agreement concerning the patient's will and family consent. Secondly, the head of surgery in the concerned department had probably made the decision to remove patients from respirators alone, without checking with other medical staff. Thirdly, voices calling on hospitals or the nation to establish rules increased.

In regard to organ transplant after brain-death, we at least have one law in Japan, though it is not such a good one ("The organ transplant law" introduced in 1997); in connection with this law there are also "Regulations for execution of the law," "Application guidelines," and "Manual for legal judgment of brain-death." Although several problems still remain, rules were established which allowed, up to the beginning of this September, 60 cases of organ transplants after brain-death was determined. World-wide, the character of this law is rare, because it makes possible a transplant after brain-death not by defining brain death as the death of the person himself uniformly, but rather via two presuppositions—first, the expression of the patient's will in writing, and second, the agreement of his or her family—and after ascertaining certain medical conditions such as brain-death. (In other words, without fulfillment of the two presuppositions, not only will an organ transplant be disallowed, but even a judgment of brain-death cannot be made.) The judgment of brain-death (in the third person) only being carried out when both presuppositions—the expression of the patient's will (in the first person) and the agreement of his or her family (in the second person)—have been fulfilled could be said to reflect Japanese culture. But, on the other hand, because even the judgment of brain-death cannot be made if either the patient's will or family agreement is lacking, it leaves behind unresolved problems in many cases of terminal care after "brain-death" (we can't call it "brain death" because we aren't legally allowed to make a judgment).

Unlike organ transplant after brain death, there are no rules in Japan for medical treatment in terminal cases. There is only the criminal law that declares assisted
suicide a type of murder. Beyond it, however, there are only three conditions for stopping life-prolonging treatment (death with dignity) and four conditions for legitimate euthanasia—all of which arose from judicial precedent from a case involving the hospital affiliated with Tokai University in 1995—and are obliging to a certain degree. Nevertheless, I am not of the opinion that a law should be introduced as the former Japanese Society for Euthanasia thought, or such a law for euthanasia as in the Netherlands and Belgium, or a law for death with dignity (assisted suicide) as in the U.S. state of Oregon, because such laws would “work” differently in Japan than in countries in which there is a culture of individualism and the family doctor system works well. A law in Japan should be one that takes Japanese culture and the Japanese medical system into consideration, just as the organ transplant law does. In my opinion, there could be, in the treatment of terminal cases, a rule similar to the one in the case of brain death and organ transplants.10

One could ask how we can make the best use of the two Japanese conditions of patient’s will and family agreement (putting aside medical judgment) as are established in the case of organ transplant. Corresponding to donor cards for organ transplants, there is a “Manifesto of death with dignity (living will),” which the Japan Association for Dying with Dignity has made. Its popularity is spreading, with the number of registered already exceeding 110,000. However, this manifesto contains problems in all three of its points (unfortunately, here I do not have space to enter into them). Also, the one-sided style of this manifesto (it includes neither family signatures nor a space for doctor authorization) is not obliging legally at all, and even if a doctor wishes to respect the patient’s will, he will have difficulty doing so in fact. I rather find the patients’ “advance directives” far more recommendable. They have even more precise contents, make provisions for two representatives (family members possible) and a doctor to sign, and make detailed choice about methods of treatment possible. There is also a blank for free expression of any personal wish. Although some problems still remain with the use of these advance directives, I believe they should be given a legal footing.

10, It is pointed out that Japan is late in establishing laws related to bioethics, including laws in the field of reproduction-assistance.
In May, the *Japanese Ministry of Health, Labor and Welfare*—published “Guidelines for decision process of medical treatment in the final stage.”\(^{11}\) It states: first, a team of caregivers composed of experts from multiple medical fields should, taking into consideration the patient’s personal decisions, make a careful decision—one that is medically reasonable; secondly, as much as possible, a patient’s pain and discomfort should be reduced, and comprehensive medical care that offers mental and social support for the patient and family should be provided; thirdly, in no case should one involve active euthanasia or assisted suicide in medical treatment. Furthermore, one should make judgments on terminal medical care while differentiating between the following two cases: one in which the patient’s will can be ascertained, and one in which it cannot.\(^{12}\) In the first case, the patient’s will as expressed in an informed consent should be the basis for further and sufficient discussion between the patient and the medical caregivers, through which the patient’s will is reconfirmed—and his thoughts on treatment, assuming his condition changed, were also clarified. In the second case, caregivers should ascertain as much as possible the patient’s will through conversation with his or her family or others. If that proves difficult, caregivers should, while consulting the family, select the best treatment for the patient. Finally, in a case in which the patient and the medical team cannot come to an agreement, or in which opinions of the team are split, the team should establish a committee of different experts in the hospital and ask for counsel.

It is pointed out that because the terminal stage of an illness is not clearly defined—who makes the judgment and with what criteria?—the Ministry’s guidelines might be not useful in clinical situations. Nevertheless it can be considered a small but important step in care for terminal illnesses; though not a law, it offers guidance that medical personnel should follow. Besides its main text, this guideline contains an explanatory part that introduces information that might have been discussed in the committee. I would like to point out some important issues mentioned in it: (1) What kind of states should be designated terminal is a matter which requires appropriate and


\(^{12}\) The case where patient’s will can’t be ascertained includes various cases, such as senile dementia, brain-death or vegetative states, newborn baby with heavy disabilities, psychic disorders, intractable neuro-diseases e.g. ALS. Exactly we had to discuss them differently.
adequate judgment on the part of the medical care team—judgment based on patient’s
cases; (2) Family implies a person whom the patient trusts and who assists him or her
in the final stage; it is not necessarily limited to mean only a relative in law, but
includes persons in a broader range. (3) If the patient, his or her family, and the
medical care team arrive at an agreement on care, it should be respected as the best
medical care for the terminal patient. Although it is not stated in the main text of the
guideline, it is implied that the ultimate goal is to reach agreement among the patient,
his or her family (in the wider sense), and the medical care team.

Just when discussion was beginning on this guideline, the Japanese translation\textsuperscript{13}
of Human Death and Self-Decision, Interim Report of Council Ethics and Right of
Modern Medicine, Advanced Directives\textsuperscript{14} of the German Federal Parliament was
published. This report made clear that the situation in Germany was different from
that in Japan.

4. Discussions about advance directives in Germany

This German report states that the “collapse of the traditional family” is a key
feature of contemporary German society. With this “change in society” as background,
the report states: “Such advance directives make sense, as far as we can clarify in
writing agreed-upon opinions and matters which family members discussed with one
another. For such reasons, the report proposes a concrete law to regulate patient’s
advance directives legally.

In comparison to the above-mentioned guideline in Japan, it strikes me that the
German report not only proposes rules for a patient’s advance directives, but also tries
to think the problem through from the ground up and in a wide context—what can be
characterized as typical German thinking. In the report summary, the following is
stated: “It is crucial to improve the system for accompanying seriously ill and dying
people as well as to enrich the palliative care and the hospice organization. The debate
on patient’s advance directives must always be embedded in this context.” The report’s

\textsuperscript{13} Trans. By Tatsu Yamamoto et al., Chisen-shokan, Tokyo, 2006.
\textsuperscript{14} http://www.bundestag.de/parlament/abkurzungen/kommissionen/
introduction includes the following statement: “Questions related to the patient’s advance directives must be seen in the total context of accompanying the dying (Sterbebegleitung) and palliative care.” Moreover, the context is widened, as far as it is not yet well handled in this report, as follows: “The further going questions of accompanying the dying, including the satisfaction of physical, mental, social, and spiritual needs, are not grasped by many advance directives.” This is something that needs to be understood clearly about advance directives.

This report confirms the right to make decisions by oneself (self-decision) on the one hand—“making decisions by oneself is a basic human right”—but on the other hand, does not forget to add that it should not be considered in isolation. More specifically it reads: “Patients’ advance directives should be interpreted giving consideration to more general ideas, such as the freedom of individuals, human welfare, duties of doctors and nurses, rules based on the right of patients, medical effectiveness and so on.” This is a different position than the one taken by those in the field of liberal bioethics in English-speaking regions, who puts priority on the right to make decisions concerning oneself and recognizes the individual’s will as much as possible—as long as it does not damage others.

I am reminded of the report preceding the above-mentioned one, that is, Human Dignity and Genetic Data—Final report of the commission of the German Federal Parliament on the law and ethics of the modern medicine (2002). First, it mentions the concept of human dignity (Menschenwürde) as outlined in the first chapter of the German Constitution, and then, from that historical perspective, it defines human beings as “both free and dependent.” The report further reads: “People have a physical existence, they are imperfect and vulnerable beings, and we must guarantee that people who need care are respected.” “As human beings, they need not possess any special qualities or abilities to have their rights to human dignity guaranteed and protected. Whether old or young, strong or weak, ill or healthy—every person has the right to have his or her dignity respected.” “Every person is dependent on the support of others, in many phases of his or her life (e.g., childhood, illness, old age), in order to have his or her individual freedoms guaranteed.” Here the point of view that not only are people

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independent, having the right to make decisions by themselves, but also that people are weak, vulnerable, and imperfect beings who must rely on the assistance of others, is made clear. The attitude exhibited in this German report, then, is that patients’ advance directives should be considered keeping in mind both sides of human beings.

5. How about it in Japan?

I would now once again like to focus on today’s situation in Japan and examine the “Report from “On terminal care again,” by the the Ninth Meeting on Bioethics of the Japanese Federation of Medical Doctors, published in February of the last year. To me, what is important to note in the report is not only “respecting patient’s will,” but also “discussing the matter with medical personnel so that also the family understand the matter and come to a consent.” The report states: “In terminal care, especially when the selection of treatments becomes a matter of life and death, or when treatment at home or in an institution are options, the decisions involved are not only issues for the patient, but also for the family supporting him or her. It is desirable that the patient not make decisions alone, but to make a decision after sufficient discussion with family.”

This Japanese report also points out some problems with patients’ advance directives. For example, “Patients’ expectations are not always reasonable.” “There are cases in which patients’ situations change from the time their advance directives are written to the time the directive is to be followed.” “The manner in which advance directives are accepted needs to be examined.” “There will always remain a variety of opinions regarding life expectancy forecasts or possibilities for recovery.” These remarks show that a check of medical validity is necessary for patients’ advance directives.

In August of this year, an interim report was issued by the above-mentioned Meeting on Bioethics: “A proposed guideline for medicine in terminal cases”—and opinions regarding it were solicited through the end of this September. There are no

16 http://www.med.or.jp/nichikara/seirin17.pdf
17 http://www.med.or.jp/nichikara/iken/info.html
big differences in fundamentals from the guidelines of the Ministry of Health, Labor and Welfare, but the following aspects of the August proposed guidelines deserve attention: (1) “Even in cases in which confirmation of the patient’s will is impossible, if there is a ‘patient’s advance directive’ the medical care team should consult with the family and determine whether or not it is still valid.” This is the first guideline to mention patient's advance directives. (2) In all cases, confirmations, agreements, and disagreements among family and others should be in writing. (3) In cases in which the terminal patient refuses life-prolonging treatment, or in cases in which the patient’s will cannot be ascertained and the family refuses life-prolonging treatment, a system needs to be created that ensures that the act of refusing life-prolonging treatment leads neither to civil nor criminal responsibility. In each of these points, despite its call to systematize respect for the will of both patients and families, this latest proposed guideline displays an intent to defend and protect doctor's rights.

I would like to come back to the problem of family in Germany. I’ve said that the German report started off by mentioning the “collapse of the traditional family.” Although expressions like family or relatives (Angehörige) appear in it, they are not stressed; rather, expressions like agent (Betreuer) or representative (Bevollmächtigter) are prevalent. Because this report tries to focus on the relationships among people—or the interdependence of people—it exhibits a different position from the one found in bioethics in English-speaking areas, which greatly emphasizes the right to make decisions for oneself. Nevertheless, it holds that this relationship or interdependence cannot be understood any more in the form of family. In Japan, however, we cannot yet, in my opinion, throw away the point of view of the second person of family, relatives, and friends.

Thus, in Japan, advance directives of the patient (the first person), the consent of his or her family (the second person), and the judgment of medical personnel (the third person) all have their place—and it is necessary for these “three persons” to communicate mutually and to create a consensus through discussion. In my opinion, this is not, for Japan, a bad way to approach the issue.

Conclusion
Unlike care for “living” persons, care for “dying” persons seems to present issues which relate to the extreme north of phenomenology. Even if death is considered an event that occurs in a relationship, caring for a dying person in the first person (that is, myself), caring for a dying person in the second person, and caring for a dying person in the third person present different problems, though those problems are related. The I who is caring for a dying person in the first person cannot do a lot. What the I can do is leave a record of his will to others in advance. But the I cannot decide his will only by himself, but as a part of human relationships in which he has lived up to now, above all, in relationships with family or friends—who themselves stand in the position of caring for a dying person in the second person—and in relationships with medical personnel—who stand in the position of caring for a dying person in the third person. The I must come to an understanding with others through communication.

I would like to say one more thing. According to the idea on palliative care of the World Health Organization (WHO), “caring for dying persons” means: “We should neither assist in accelerating nor assist in delaying death.” Palliative care aims neither at euthanasia nor at prolonging survival time. In German, there is an expression, Sterbebegleitung (“accompanying the dying”)—this appears in the abovementioned report—which contrasts with the expression Sterbehilfe (“helping the dying”). Sterbebegleitung means keeping in step with the patient as he approaches death, and being with him at the moment he, with full spirit, welcomes death. The third person also “supports” the dying. This, then, is my opinion on caring for a dying person.

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