

"Death with Dignity" in the Japanese Context

Motomu SHIMODA

(Osaka University Graduate School of Medicine, Department of Medical Ethics)

Introduction

In Japan "death with dignity" [=DWD] or "dignified death" is a widely known term that is distinguished from "euthanasia." Mass media reports on euthanasia cases often comment that;

"Euthanasia in its broad sense is the practice of ending the life of a patient suffering from a terminal and incurable disease by lethal injection (active) or withholding or withdrawing life-sustaining medical treatment (passive), and by relieving suffering by shortening their life as a consequence (indirect), either voluntarily (at the patient's request) or non-voluntarily (without the knowledge or consent of the patient). DWD, on the other hand, is the act of allowing a terminally ill patient or one in a persistent vegetative state [=PVS] to die with dignity by withholding or withdrawing life-sustaining medical treatment as requested in the form of a living will [=LW]."

While some say that DWD can be classified as voluntary passive euthanasia [=VPE], others claim that it is not a form of euthanasia because the term "euthanasia" is limited to voluntary active euthanasia [=VAE]. This conflict arises due to the different views held on the definition of euthanasia. There is no common understanding of euthanasia in the world or in Japan. Based on the situation concerning euthanasia in some western countries, I would define the word as follows:

"Euthanasia is the practice of another person(s) ending the life of a patient suffering from a terminal and incurable disease or of a person with intolerable suffering."

DWD mentioned above is a particular form of euthanasia, and this includes the intentional termination of a patient's life through the compassion or mercy of another person(s) regardless of the patient's will (=mercy killing). Physician-assisted suicide [=PAS], however, is distinguished from euthanasia because it is the patient himself/herself that terminates his/her own life by a lethal dose prescribed by the physician.

At any rate, most Japanese people consider DWD a desirable way of terminating one's life and therefore acceptable as a "natural death" or "humane death." Originally, DWD was regarded as a passive intervention, but since the 1990s, its connotation has changed in western countries such as the USA and the Netherlands etc.; VAE and PAS should be legalized in the name of DWD or aid-in-dying with dignity. In this paper, I

examine the points and problems of this new type of DWD, and propose an alternative version of DWD especially in the Japanese context.

1. Classical Version of DWD

The establishment of the concept "DWD" can be associated with two major events in 1976 in the USA: the New Jersey Supreme Court ruling on the case of Karen Ann Quinlan and the California Natural Death Act. The former admitted that "right to privacy" involves the patient's right to refuse life-sustaining treatment and enables doctors to remove a respirator. The latter legalized LW which grants the withholding or withdrawing of life-sustaining or life-prolonging treatment in connection with the "dignity and privacy of the patient." After this, other states in the U.S. followed California, and in 1981, the World Medical Association Declaration of Lisbon on the Rights of the Patient stated that, "The patient is entitled to humane terminal care and to be provided with every available assistance in making dying as dignified and comfortable as possible."

It was when a major newspaper (Asahi-Shimbun) reported the New Jersey Supreme Court ruling on the Quinlan case in April 1976 that the term "death with dignity" was used for the first time in an official capacity in Japan. In that article, DWD meant the right to stop life-sustaining treatment of a PVS patient as the right to privacy. People in general have accepted the term as distinct from euthanasia, but it did not become common and gain in popularity at that time.

The Japan Society for Euthanasia, founded in January 1976, aimed at legalizing VPE and disseminating the LW of terminally ill and incurable patients, though the central character, an obstetrician and gynecologist Tenrei Ohta, claimed it promoted VAE and PAS. The basis for establishing this policy was the concern that by legalizing VAE and PAS, murder for the convenience of family members or the medical profession could be conducted frequently in Japanese medical circles in which terminating a patient's life at the request of family members was common practice.

The Japan Society for Euthanasia, which changed its name to the Japan Society for Dying with Dignity [=JSDWD] in 1983, has targeted propagating and popularizing LW in the "Declaration for Dying with Dignity." (Membership of the Society or enrollment for the Declaration topped 100,000 in 2002.) ¹

Its main requests are:

¹ cf. <http://www.japantimes.co.jp/cgi-bin/getarticle.pl5?nn20021217a5.htm>

- (a) Refusing unreasonable life-prolonging treatment at the terminal and incurable stage,
- (b) Desiring palliative medicine despite life shortening as a consequence,
- (c) Hoping for the withdrawal of the life-support system in PVS. ²

The reasons for these choices as claimed by the registrants are "not to become a burden to my family members," "to reject a life with no quality" etc.

The Japan Medical Association expressed respect for the LW of JSDWD and acknowledged its validity in 1992, and the Science Council of Japan also recognized DWD in 1994. Some public opinion polls show that more than 60% of people support DWD in this sense. Some jurists, however, assert that PVS should not be regarded as an indication of DWD because it is not terminal disease.

"Dignity" presupposed here does not imply special value as "sanctity" or "inviolability," "end in itself" or "nonsubstitutability" connected with life or humanity. Rather, it indicates attributes associated with an individual person having the "right to privacy" or "self-determination." We should note that it conveys an evaluation of life since it refuses life-sustaining treatment at the terminal and incurable stage or PVS as the "futile prolonging of a life-devoid-of-dignity."

2. Transformation of DWD: From "Right to Refuse Life-sustaining Treatment" to "Right to Die"

Since the 1990s, DWD has gained positive connotations in the USA and some other western nations; the right to die in the form of VAE and PAS has been advocated as DWD. First, let's survey the U.S. situation, and then major movements of other western nations.

In the 1990 U.S. Supreme Court Ruling in the case of Nancy Cruzan, who was left in a vegetative state after a car accident in 1983, justices allowed her family to remove the feeding tube or acknowledged the right to refuse treatment in the name of the right of privacy or the right of self-determination. After that, the Patient Self-Determination Act was enforced in 1991 by the U.S. federal government, which allowed an advanced directive as the individual right of self-determination. Both retained justifying the "right to die" as the passive right to refuse life-sustaining treatment or the classical version of DWD.

An official action for the active right to die was started in the State of Washington,

² cf. <http://www.songenshi-kyokai.com/>

in which "Initiative 119" was put to a referendum but rejected in 1991. That bill aimed to give patients in a terminal condition the right to request aid-in-dying in the form of VAE and PAS, which would have been the "Washington Death with Dignity Act." A similar bill, "Proposition 161," which would have been the "California Death with Dignity Act," was also rejected in the State of California in 1992. In 1994, however, people in the State of Oregon voted for the bill, which allows only terminally ill patients to obtain and use prescriptions from a physician for lethal drugs, but not VAE, (because of a protest movement), which was enforced as the "Oregon Death with Dignity Act" in 1997. ³

Some nongovernmental "right to die" campaigns are behind these movements, e.g.:

(a) The Hemlock Society, founded in 1980 and now End-of-Life Choices, claims "We work for the freedom to choose a dignified death and for individual control concerning death." ⁴

(b) World Federation of Right to Die Societies: Ensuring Choices for a Dignified Death was founded to provide "an international link for organizations working to secure or protect the rights of individuals to self-determination at the end of their lives" in 1980. ⁵

(c) The Death with Dignity National Center, set up as a network for enacting the DWD act as in the State of Oregon in 1994, strives to legalize PAS. ⁶

Also in some other western nations, there are trends advocating the "right to die" in the name of DWD, in which VAE and PAS are asserted as being legalized. Moreover, the indication is not only for patients with a terminal and incurable disease or PVS, but also persons with mental suffering or intractable neuron disease such as ALS -- both of which are not terminal conditions. This tendency occurs in the Netherlands and Belgium, where VAE and PAS have been legalized. The Netherlands, in particular, enacted "The Termination of Life on Request and Assisted Suicide (Review Procedures) Act" in 2001. "Q&A Euthanasia," a Dutch Government Website, states that "Pain, degradation and the longing to die with dignity are the main reasons why patients request euthanasia." ⁷ "Intolerable pain" includes not only terminal and incurable disease or PVS, but also intractable disease, serious dementia or incapability of leading an independent life.

³ cf. http://www.nightingalealliance.org/htmdocs/iss_index_a.htm

⁴ cf. <http://www.hemlock.org/index.jsp>

⁵ cf. <http://www.worldrtd.net/>

⁶ cf. <http://www.deathwithdignity.org/>

⁷ cf. http://www.minbuza.nl/default.asp?CMS_ITEM=MBZ461025

On the other hand in the U.K., a woman paralysed from the neck down by advanced motor neuron disease requested active aid-in-dying by lethal injection in 2001 -- the case of Diane Pretty. She said, "If I am allowed to choose when and how I die, I will feel that I have wrested some autonomy back and maintained my dignity." ⁸

And in Switzerland, assisted suicide is not illegal because the practice of helping a terminally ill patient to end his or her life is widely considered as a humane act. "Live with dignity, die with dignity" is the slogan of Dignitas, the Swiss organization for assisted suicide founded in 1998. ⁹

Let me sum up the points of this new version of DWD. First, the connotation of the "right to die" has transformed from the passive "right to refuse life-sustaining treatment" to the active "right to VAE and PAS." Such direction is inevitable in my opinion, and "Rational Suicide" may be an ideal of this DWD concept. Its basic criteria are (a) hopeless condition, (b) free of coercion, and (c) sound decision-making, in which it makes no difference whether or not the patient is terminally or incurably ill,-- and the preferred method of ending one's life is performed under one's control without the aid of any other person(s). ¹⁰

Secondly, as a necessary consequence of the first point, what's important here is to terminate a "life-devoid-of-dignity" or "life with indignity" derived from evaluating the quality of human life. ¹¹ This means that the method of ending life -- passive or active -- is merely a subsidiary issue. Life-devoid-of-dignity implies a "life not worth living," "life with undesirable conditions," and viewed from another angle, "fear of losing control over one's life" is a decisive factor for such evaluation.

It follows that self-determination of how to die and under which conditions to choose to die is essential for this way of thinking. Desire for control over one's life and death might be the driving power of such thinking. When the concept "dignity" is associated with the right to privacy or views about death, defining a "life-devoid-of-dignity" or "condition not worth living" is regarded as a personal matter. This evaluation would be expanded from individual physical or mental conditions to include the relation with other persons such as "burden on family members," as noted in the discussion on the situation in Japan, which shall be dealt with in the following section.

⁸ cf. Reuters News website, 2001/11/28

⁹ cf. <http://www.dignitas.ch/default.htm>

¹⁰ cf. http://www.ashbusstop.org/2b_ratsui.html

¹¹ cf. Cohen-Almagor, R., *The Right to Die with Dignity : An Argument in Ethics, Medicine, and Law*, Rutgers University Press, 2001, chap.1; Allmark, P., Death with dignity, *Journal of Medical Ethics*, 2002 Aug Vol. 28, Issue. 4

3. New Development in Japan from the 1990s

In the 1990s, the patients' rights movement developed out of the pursuit of acquiring the patient's right of self-determination. It seems that in Japanese medical custom, paternalism has been dominant and unreasonable medical practices have not been unusual for the convenience of the medical side as a profit-making enterprise or as the subject of clinical studies. In contrast, the ideology of "lifesaving and life-prolonging treatment should be pursued as long as possible" has also been dominant, which could be considered as self-satisfaction of the medical staff. In addition, the request by family members for "take best measures to support life" should be rejected if it disturbs the patient's "ending of life in my own way." On the JSDWD website, you can see that DWD is not the "putting of someone to death" by others but a "way of dying by one's own values."

Some citizens' groups such as the Citizens' Group for Considering End-of-Life (1990-), the Japan Association for Hospice and Home Care (1992-), and the Study Group for Let Me Decide (1993-), aim at popularizing LW or advancing directives including proxy instruction.¹² And academic movements of "thanatology" and "death education" have been spread among the general public in response to the needs for "dying in my own way."

Certainly, those trends are oriented to DWD in the sense of the right to refuse life-sustaining treatment in the terminal and incurable stage. But corresponding to the change in the USA and Europe, active aid-in-dying has been more influential than before. It was the ruling of the District Court of Yokohama (1995) that became an epoch-making judicial judgment in regard to both types of DWD in Japan. In that ruling, stopping medical treatment for a terminal and incurable patient under the condition of clear intention or LW, or the presumption of the family was admitted. On the other hand, active euthanasia was also admitted under the following conditions: (a) intolerable physical pain, (b) terminal and incurable condition, (c) no alternative measures to relieve the pain, (d) clear intention of request for dying. Up to now, however, no single case has been justified as satisfying these four conditions in Japan.

Furthermore, we find an expansion of the condition requesting DWD. In a questionnaire concerning applying DWD to serious elderly dementia sent to the

¹² See the following websites but only in Japanese.

<http://www6.ocn.ne.jp/~syumatuk/>

<http://www.hospice.jp/index.html>

<http://www1.doc-net.or.jp/~ninosaka/>

members of JSDWD, about 85% of respondents were in favor of that proposal. The reasons were "I don't want to trouble my family," "life is not worth living," etc. That proposal was, however, rejected as being premature -- and it was difficult to gain public understanding -- by the executive office of the society in 1997. That report suggests the possibility of expanding the range for "life-devoid-of-dignity."

Thus, I would like to point out two crucial factors from this report. First, in Japanese medical practice, family members' intentions are often more influential than the patient's autonomy, -- many physicians provide the facts to the family members first but not to the terminally ill patient. If the family asks physicians not to tell the patient the truth, many physicians will agree to this request, -- and also many patients accept this as standard practice. So the main reason for requesting DWD is not the patient's self-determination, but "I don't want to become a burden on my family members by my life-sustaining treatment." Dementia and other intractable diseases can also be regarded as a "burden on family members."

Secondly, the eugenic way of thinking has remained influential since the 1930s in this country, and the Eugenic Protection Law (1948-1996) legalized sterilization or abortion for eugenic reason. Leaders of JSDWD have insisted that terminally ill and incurable or PVS patients are "not worth living," a "burden on the family or an unnecessary cost for the community," and life-sustaining medical treatment for that patient is "futile and wasteful," so terminating their lives should be legalized. It is not "reducing inferior genetic traits" as in classical eugenics, but "eliminating the inferior quality of human life," -- which is also a form of eugenics.

These two factors, the ideas of "burden" and "unworthiness," play a major role in discriminating attitudes against disabled people or patients with serious disease in need of help. Many people in general believe that they would rather die than have their lives become a burden to their family. Connected with the social cost and productivity oriented way of thinking, that belief would function as an excluding power against the life in need of help and cost. It could be a real threat to such vulnerable people.

Advocating a patient's self-determination in order to conquer the paternalistic and conventional attitudes prevailing in Japanese medical practices is therefore a distinct necessity. However, we have to be cautious about the impact of that direction on the social values behind the concept of DWD, which is likely to promote the exclusion of people labeled as "burdensome" or "unworthy."

4. An Alternative to DWD as Termination of Life-devoid-of-Dignity: DWD as

End-of-Life Care Process in Support of Life-with-Dignity

I have summarized the new version of DWD as the "voluntary termination of life-devoid-of-dignity" in the previous sections. However, is it possible to refer to "voluntary termination of life-devoid-of-dignity" as dying "with dignity"?

Among other questions, we should ask why the person regards him/herself as having a "life-devoid-of-dignity." That evaluation may imply that "sustaining or prolonging such life is violating my personal dignity," or "terminating such life will bring about my liberation from suffering." Would responding to those requests of these persons be aid-in-dying with dignity? If the termination is performed for that reason, it would be ending life because of its indignity, not dying "with dignity" in any sense. I would like to propose an alternative to this kind of DWD with the help of the end-of-life care approach. ¹³

In Japan, many medical professions engaging in end-of-life care or terminal care insist that "supporting a patient's end-of-life by total care to maintain dignity in the terminal stage should be given priority, and that would realize DWD in the true sense of the word." If a terminally ill patient requests to put a stop to such a miserable and inhuman life, medical staff should try and obtain an insight into the real meaning behind that appeal and search for ways to make end-of-life-with-dignity possible. And if a person with intolerable suffering wishes for active euthanasia or assisted suicide, those around him or her should turn their attention to the background behind his/her request and try to improve it. Advocates of this approach claim that we need psychiatric care for a person wishing suicide, palliative and comfort care including sedation for terminally ill patients, mental and economic support for their family members, and a local network for supporting the system with nursing-care services.

However, this concept of DWD as "end-of-life care for life-with-dignity" has been strictly criticized by the advocates of the new version of DWD or the right to die supporters;

since the evaluation of dignity varies among individuals, DWD depends on the views of life and death on the basis of that evaluation, and whether or not end-of-life care or terminating life without delay is determined by the person concerned; --

¹³ cf. Street A, Kissane, D. Constructions of dignity in end-of-life care, *Journal of Palliative Care* 2001;17:93-101; Chochinov, H.M., Dignity-conserving care--a new model for palliative care: helping the patient feel valued, *JAMA* 2002 May 1;287(17):2253-60; Ellershaw J, Ward C, Care of the dying patient: the last hours or days of life, *BMJ* 2003 Jan 4; 326(7379):30-4

end-of-life-care is merely an option. ¹⁴

It is true that there is some suffering that cannot be relieved by any kind of medical treatment and care, but despite this, medical staff or those related to the sufferer are not allowed to abandon the possibility of maintaining life with dignity. Listening to the cry for aid-in-dying of "let me die in my own way" in order to be liberated from misery is not the same as accepting the right to die and helping the person to end life. We must be careful about the relation between individual self-determination and the interactive and social implications with respect to aid-in-dying;

(a) Easy access to death at the request of the person might hinder improving the system or structure which continues to produce "misery."

(b) Individual evaluation of quality of life could affect the social values of the general public toward people with "burdensome" or "unworthy" conditions.

(c) No one has the right to involve others including family members in aid-in-dying.

Conclusion

In conclusion, I would like to show the basis of my argument for the alternative version of DWD, i.e. end-of-life care process in support of terminal living with dignity.

As has been mentioned, the DWD movement started from the "right to refuse futile life-sustaining treatment" to the "right to VAS and PAS" -- that is an unavoidable expansion of the desire for the "right to die." DWD as "the active termination of life-devoid-of-dignity" is more influential in the USA, Europe and Japan nowadays. However, it is the "right to provide sufficient end-of-life care for terminal living with dignity" that should be given priority over the "right to die." Especially in Japan, the "right to self-determination in ordinary medical treatment" and the "right to hospitable and sufficient end-of-life care" needs to be immediately established. Furthermore, we have to be cautious about the social implication of the individual desire for dying with dignity; the prevailing evaluations of "burdensome" or "unworthy" might be reinforced by individual self-determination. That is, in my opinion, a crucial point when considering the meaning and significance of the concept of DWD in the Japanese context.

¹⁴ See Dutch government website "Q&A Euthanasia"; "Dutch health care system is accessible to all and guarantees full insurance cover for terminal and palliative care. Unfortunately, even where patients are receiving care of the highest quality, they may still regard their suffering as unbearable and plead with their doctors to terminate their lives. In such cases, euthanasia could represent a dignified conclusion to good palliative care."