

# Withholding/Withdrawing Treatment to Neonates Born with Impairment

## Best Interest, Medical Futility, and Distributive Justice

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### ABSTRACT

This paper examines the ethical justifiability of withholding / withdrawing treatment to profoundly impaired neonates. First, we explain that treatment for impaired neonates has special characteristics precisely because impaired neonates lack “autonomy”. We then consider the notion of the best interest and point out that it cannot justify withholding / withdrawing treatment to impaired neonates because the interest of other persons such as parents cannot be morally justified. Moreover, we consider the notion of medical futility in the following manner:

(1) ‘Physiological futility’ used with ‘imminent demise futility’ is the only objective definition of medical futility. (2) Yet it is insufficient since the decision-making of withholding / withdrawing treatment also requires ‘a normative social context’ that concerns the value of human life, namely ‘normative futility’. (3) The claim that we should restrict futile treatment based on cost-effectiveness evaluation or ‘distributive justice’ has both a medical and a normative nature, but even distributive justice cannot justify withholding / withdrawing treatment to impaired neonates insofar as the present state of pediatrics or the environment of social participation of disabled persons in Japan is concerned.

Finally, referring to disability studies, we conclude that there are no ethically justifiable grounds for withholding / withdrawing treatment to impaired neonates that have priority over their right to live.

**Keywords:** lack of autonomy, best interest, medical futility, normative futility, distributive justice, cost-effectiveness evaluation, disability studies

## 1. Absolute lack of “autonomy”<sup>1</sup>

The ethical validity of withholding/withdrawing treatment to neonates with impairment has been publicly argued since Duff and Campbell published a paper in 1973 (Duff [1973]). They reported 43 newborns of 299 who passed away at Yale-New Haven Hospital, from January to June of 1970. The 43 newborns died as a result of withdrawing treatment and these particular cases complied with the hospital policies for care. These cases were alarming because they revealed the fact that withholding/withdrawing treatment to neonates with impairment had been practiced in secret and with the tacit consent of the people involved. This secrecy and lack of transparency

started a public discussion about the moral justifiability of such a medical policy.

Duff and Campbell further reported the actual state of withholding/withdrawing treatment to neonates with impairment in the USA, but similar measures have been applied in other countries. In Germany, the “Einbecker Empfehlung”, adopted by German Association of Medical Law in 1986, admitted withholding/withdrawing treatment to neonates with impairment under certain conditions. In France also, the National Ethics Advisory Committee Report No.65 announced findings that withholding/withdrawing treatment to neonates with impairment was routinely practiced (Sawano [2012:296]).

In Japan, according to a survey conducted by

The Asahi Shimbun (answered by 25 physicians of 40 hospitals), 24 physicians replied that they had determined withholding/withdrawing medical treatment to neonates with impairment depending their symptoms (Koyama [2012:17]). Needless to say, the most important question, in the context of neonatal impairment, is ‘Under what conditions may physicians consider withholding /withdrawing treatment to neonates with impairment and be ethically justified in doing so?’

More recently, a public opinion poll in 2013 in Japan showed that over 81% of respondents did not want to receive life-prolonging treatment at their terminal stage, and 82% of responding hospitals in Japan acknowledged having withheld or withdrawn life-prolonging treatment of patients at the terminal stage<sup>2</sup>. As we can see even from these few factual sources, a general social agreement has already begun to coalesce, regarding ‘death with dignity’<sup>3</sup>.

In considering death with dignity at the terminal stage, however, we must note that the decisive power must be solely in the patient’s hands; under what condition he (she) would prefer death with dignity depends on the patient’s own view of life and death. In fact, the guideline announced by the Ministry of Health, Labor and Welfare (following MHLW), in 2007, made it clear at the start that “the decision made by a patient” is the fundamental requirement. The “Gesetz über Patientenverfügungen” in Germany<sup>4</sup>, which legalized advance directives, also respects the intention of the patient as much as possible. Moreover, respect for the patient’s right to self-determination is common to all similar laws, including “The Patient Self-determination Act 1990”; as a result, the opinion that self-determination based on a patient’s autonomy is an indispensable requirement to justify withholding/withdrawing treatment prevails globally<sup>5</sup>.

However, invoking the right of self-determination for impaired neonates is, by definition, impossible, since neonates do not possess any cognitive competency (Tamai [1996:492f]). Further, in contrast to normal neonates who are expected to become competent in the future, neonates with severe intellectual impairment cannot even be considered as potentially competent agents because they lack

even the possibility of cognitive competency. Therefore, we have to distinguish the problem of withholding/withdrawing treatment to neonates with impairment from other cases because impaired neonates lack any autonomy. Accordingly, the main question of this paper should be the following: ‘Since autonomy is impossible, even in potential form, how can we ethically justify withholding/withdrawing treatment to neonates with impairment?’

## 2. In the best interest

The first researcher in Japan who published the standards for withholding/withdrawing treatment to neonates with impairment was Hiroshi Nishida. He played a central role in making the so-called “Tokyo Women’s Medical University Guideline” (Nishida [1986]), which was divided into four classes as follows; Class A, doing all the possible treatments, Class B, withholding an operation on heart or dialysis, Class C, doing only general nursing, and Class D, withdrawing all the treatments. Nishida’s classification was only a private manual used initially at one hospital, but it came to be interpreted as if it were an officially authorized guideline (Tamura [2005:6]). Because of the rapid progress of pediatrics the NICU experienced, the Tokyo Women’s Medical University Guideline became a standard for other facilities (Tamura [2005:72]). However, there are problems with the Nishida Guideline.

Nishida’s classification names specific diagnoses, such as epidermolysis bullosa, congenital myopathy, trisomy18, and so on; however, this categorization by disease or condition could allow physicians to commit automatically to withholding/withdrawing treatment, as soon as a diagnosis has been determined. Worse, listing of diseases and conditions could result in a kind of ‘cessation of thinking’ or unconditionally refraining from aggressive treatments for neonates born with 18 trisomy. Approximately 90% of neonates born with 18 trisomy die within one year, but there are some -admittedly rare- cases, when a neonate born with 18 trisomy grew up to enter the elementary school<sup>6</sup>. Therefore, the statistical predictions do not guarantee the absolute certainty for individual cases, and such routine classification can never be morally or medically

justified.

In contrast, the “Guidelines for Healthcare Providers and Parents to Follow in Determining the Medical Care of Newborns with Severe Disease” (following GHPP), announced in 2004, is significantly different from such classifications. Though this guideline has many remarkable characteristics, let us highlight the following three points: [1] it doesn’t give any instructions about how we should decide a treatment policy, nor how we can discuss about the way of deciding it; [2] it stipulates that the parents participate in the discussion as concerned persons who have the same decision-making power as physicians, in terms of treatment decisions; and [3] its basic policy gives top priority to ‘the best interest’ of patients themselves.

Point [1] avoids the potential for unthinking medical routine that could result from categorizing neonates by disease or condition. GHPP does provide items that should be protected in a decisional procedure relating to treatment, in place of an itemized standard concerning start / continuation or withhold / withdrawal of treatments. Further, the question of who is to decide a treatment policy is entrusted to the intention of ‘the persons concerned’ in individual cases. Therefore, this guideline acknowledges the variety of symptoms or states of each patient and allows enough flexibility for persons concerned to make treatment proposals.

On the contrary, although [2] and [3] seem to be ethically desirable at first glance, an ethical problem emerges from [2] and [3], regarding the notion of ‘the best interest’, even though the concept of ‘the best interest’ is the most widely supported standard for withholding/withdrawing treatment to neonates with impairment (Weir [1984:194f]). According to AMA’s definition, we should weigh in evaluating the best interest of neonates with impairment, according to the following factors; “(1) the chance that therapy will succeed, (2) the risks involved with treatment and nontreatment, (3) the degree to which the therapy, if successful, will extend life, (4) the pain and discomfort associated with the therapy, and (5) the anticipated quality of life for the newborn with and without treatment” (AMA [1994]). From this definition, we can understand that the best interest means the comprehensive standard that contains various elements such as

quality of life (QOL), unbearable pain and so on.

Because neonates with impairment (especially cognitive impairment) lack the ability to judge their own best interest, in most cases, parents, acting as proxy decision-makers, are entrusted to presume best interest of their child. But considering that the convalescence prediction of neonatal patients is very difficult, it is doubtful whether physicians and parents can judge, with any precision, the best interest for neonates with impairment exactly. Moreover, no one can wipe out the question that ‘the best interest of parents’ (such as the economic state of the family) would affect the judgement<sup>7</sup>. At the same time, we must cope with possibility that judgement of parents may be influenced by those circumstances and they eventually give priority to their own best interest.

Because of the potential for conflict of interests noted above, as Cohen and Weir point out, we must consider very carefully who is the most qualified to judge the best interest of neonates with impairment, however, determining what person or party is most qualified is also the very difficult problem to solve<sup>8</sup>. The best interest of neonates with impairment estimated by parents, physicians, the Hospital Ethics Committee or the court is almost always imagined by those who have no impairments and have already established their own view of life and death or sense of value. Accordingly, even how hard we try to guess the best interest of neonates with impairment, we have to doubt if the judgement made without any experiences of life with impairment can really speak for the best interest of neonates with impairment. That is to say, the concept of ‘the best interest’ can become the grounds for justifying withholding/withdrawing treatment to neonates with impairment as far as their estimated interests can be imagined. However, this concept is hardly feasible or morally defensible, since those who invoke the concept are incapable of placing themselves in such a position as the neonate without autonomy.

### 3. TADA and medical futility

“The Case of Emilio Gonzalez” in 2006 made people over the world pay great attention to the viewpoint that tries to justify withholding/

withdrawing treatment to neonates with impairment based on ‘medical futility’. Emilio, born in Texas on November 3<sup>rd</sup> of 2005, started exhibiting neurological disorders a few weeks after his birth and was diagnosed with Leigh disease. On December 27<sup>th</sup>, 2006, Emilio was admitted to PICU at Children’s Hospital of Austin. After several months, the medical team treating him judged that more treatment would only “serve to prolong his suffering without the possibility of cure” (Ouellette [2011:106]) and suggested to Emilio’s mother that the aggressive treatment to Emilio should be withdrawn, but she strongly hoped for continuation of the aggressive treatment to the last.

In March, 2007, the hospital’s Hospital Ethics Committee convened, after having requested Emilio’s mother’s attendance and announced that if she could not find another hospital to undertake Emilio’s treatment, the medical team would withdraw life-prolonging treatment for Emilio. Deciding withdrawal of treatment against the wishes of the family of neonatal patients seems to be extremely unreasonable, but the unilateral withdrawal of treatment was given legitimacy by the “Texas Advance Directives Act of 1999” (following TADA). TADA, often called “the futile care act”, authorized the hospital to withhold / withdraw treatment ‘unilaterally’, that is, regardless of the intention of patient or the family when the Hospital Ethics Committee determined that further treatment would be medically inappropriate and when some other conditions are met.

TADA is an extraordinary law since it takes the standpoint that withholding/withdrawing treatment to neonates with impairment is justifiable without being restricted in the intentions of patient or the family, but solely for the reason of it being considered ‘futile’. The laws in the USA, Germany and France legalize withholding/withdrawing life-prolonging treatment at the terminal stage. Moreover, the laws in Belgium, Netherlands, Luxembourg and five American states (Oregon, Washington, Montana, Vermont and New Mexico) currently allow the physician-assisted suicide. However, none of these laws have any articles permitting physicians to take measures to hasten the end of a patients’ life when intention of the patient is

unknown and no agreement of proxy decision-maker is provided<sup>9</sup>. In short, TADA is the law with very few exceptional characteristics, making it impossible to judge the ethical validity of TADA based on the conventional argument over the laws concerning death with dignity or euthanasia. Therefore, let us determine whether we can ethically justify the concept of ‘medical futility’.

#### 4. What is ‘medical futility’?

Since the prescription of an antibiotic for the virus infectious diseases is medically meaningless, we find it difficult to deny the claim that the medically futile treatments do occur in general (Halliday [1997:148]). However, even though grounds to consider a treatment medically futile may exist, we encounter problems with definitions of ‘medical futility’, since various conflicting interpretations co-exist and a unified opinion is not yet established (Krones [2013:207]).

For example, we can distinguish three definitions of medical futility as Ouellette introduced; [1] physiological futility, based on whether a treatment brings the physiological effects, [2] qualitative futility, based on whether a treatment offers the improvement of QOL or the benefit to the patient as a whole person, [3] quantitative futility, based on the statistical prediction of the possibility that a treatment is successful (Ouellette [2011:120f]). Moreover we can add [4] imminent demise futility, based on the vital prognosis of the patient (Brody.BA [1995:208]) and [5] economic futility, based on evaluation of cost-effectiveness of a treatment (Bernheim [2013:73]). But these definitions of medical futility are mutually inconsistent or even contradictory because we easily understand that a treatment can be considered as futile according to the definition [2], whereas the same treatment can be considered as effective, according to the definition [1].

Withholding/withdrawing treatment is such an important decision-making event that the decision to treat – or not – controls the life or death of the patient and the grounds for justifying such an important decision must be supported by valid arguments. Namely, argumentative validity is the minimum condition for decision-making,



in terms of ethically justifying withholding/withdrawing treatment. So the ambiguous and multiple definitions of medical futility without consistency mentioned above, is very dangerous because of the absence of valid argumentation.

Besides, in the field of neonatology with special characteristics such as the difficulty of the convalescence prediction, it must be ethically criticized to withhold / withdraw treatment to neonates with impairment on the ground of such an inconsistent concept of medical futility.

First, we see about [3] quantitative futility. For example, Schneiderman proposes a definition of quantitative futility that a treatment should be considered futile “when it has not worked once in the last 100 times it was tried” (Brody, H [1997:3]). But Halliday argues that “very few physicians are in a position clearly to recall the last 100 uses of a therapy” (Halliday [1997:149f]). In addition, H. Brody points out the standard that “the last 100 times it was tried” is at most statistical index (Brody, H [1997:3]). In short, quantitative futility shows only a statistical or mathematical probability and cannot be a standard based on the medical evidence, it would lead to malpractice ignoring the potential possibilities of treatment if physicians decided to withhold / withdraw treatment depending on it.

Second, [2] qualitative futility is a standpoint that considers a treatment futile when it does not lead to the benefit of the patient ‘as a whole person’. For instance, Schneiderman distinguishes between an effect, which is limited to some part of the patient’s body, and a benefit, which appreciably improves the person as a whole and insisted that a treatment that fails to provide the latter is considered to be futile (Schneiderman [1990]). It is hard to say that the judgment of the qualitative futility is reliable enough if physicians (without impairment) tend to evaluate the QOL of persons with impairments lower than their own evaluation as Werth points out (Werth [2005:32]). For instance, Wall examined 121 patients who died as a result of withholding/withdrawing treatment, during a three-year period, and found that 62 patients (52%) were withheld from or had existing treatments withdrawn because physicians believed it was meaningless though the official reason given was that it did not improve their QOL (Wall [1997]). This survey result shows that we cannot deny the possibility that a QOL

evaluation is used arbitrarily by physicians.

In contrast, [1] physiological futility can be an objective standard about a very particular point, namely, whether a treatment is medically effective or not, as far as it is supported by medical evidence, not only by statistical probability. But considering seriousness of deciding to withhold / withdraw treatment, it is necessary to confirm life convalescence defectiveness by using [4], imminent demise futility. Furthermore, considering the point that the convalescence prediction of neonatal patients is very difficult, we have to make sure of the certainty of the diagnosis by ascertaining the state of them carefully and must strive to evade a ‘too hasty decision’<sup>10</sup>.

## 5. Normative futility

The right of the patient to request withholding/withdrawing treatment suggested by physicians or treatment currently in progress, when the patient thinks it meaningless, that is, ‘the right to refuse treatment’ based on the patient’s autonomy can be considered a social agreement. In the United States, the judicial decision that considered surgery performed without the agreement of the patient to be the assault occurred in 1914 (Prip [1997:40]). In Japan also, in a Supreme Court judgment of 2000 shown in a blood transfusion refusal case by the religious faith, the right to refuse the treatment of the patient was accepted.

However, circumstances surrounding ‘the right to receive treatment’ are quite different from the right to refuse treatment. While the right to refuse treatment is regarded as a ‘negative right’, the right to receive treatment is regarded as a ‘positive right’. The difference between these rights is that the former merely refuses involvement of others whereas the latter requires involvement of others and means “to oblige others to some kinds of service and consumption of resources” (Prip [1997:140]). And these two rights are conclusively different, since the former is widely accepted including the cases that bring the patient himself (herself) disadvantages whereas the latter is not always admitted without any restrictions.

H. Brody mentions “professional integrity” as the principle that can be opposed to autonomy of the patient and claimed if patients ask futile

treatment for physicians, they require physicians “to act contrary to their goals of practice” (Brody. H [1997:8]). Bernheim insists the person most qualified to judge medical futility is a physician and says “the physician has the right, and strictly speaking even the obligation, to refuse a physiologically futile treatment” (Bernheim [2013:74]).

Against these claims, Veatch objects and argues we should distinguish “normative futility” from “physiological futility”. Further, he suggests that physicians and surrogates that are disputing the treatment policy agree at least about medical diagnosis, and that they are “not disputing the facts; they disagree about the value of the extension of life” (Veatch [2013:15]). In short, the futility debate about withholding/withdrawing treatment to neonates with impairment concerning normative futility involves value judgements, but as a result of confusion between facts and values, the heart of the argument was lost sight of the persons concerned.

Halliday ([1997]) and Katz ([2011]) show more profound opinions about this point. At first Halliday doubts validity of physiological futility by saying “the more fundamental problem ... lies in the idea that the concept of physiologic futility can be ... purely factual” (Halliday [1997:150]). In addition, he notes even if it is possible to create a value-neutral definition of medical futility, its effective use requires “a normative social context” (Halliday [1997:151]) and concludes that decisions about withholding/withdrawing treatment are essentially beyond the medical profession because there is a big difference between thinking that a particular treatment will not have the intended physiologic effect and deciding that the treatment should be withheld or withdrawn. Katz also points out that the concept of futility is preceded by an important moral judgement because assessing futility requires an assessment of the value of the life and argues that science and medicine can say nothing about the value of human life, so physicians enter an area that is beyond their expertise, by invoking medical futility.

Certainly, physiological futility gives us an objective knowledge about whether a treatment is physiologically effective for those who are in the state of imminent death. However, can we immediately conclude that we should therefore

give up the treatment? When a physician insists that the further treatment is medically futile, but parent (like Emilio’s mother) of a neonatal patient still thinks that the continuation of the treatment is meaningful, the opposition occurring between them is not over a mere medical fact. Rather, it is the opposition caused by the different value-laden evaluations for the same medical fact, that is to say, an ethical conflict over the value of life.

## 6. Distributive justice

The arguments of Veatch, Halliday and Katz show that even if a treatment is judged to be physiologically futile, the medical judgement does not necessarily mean that we should therefore forgo treating the patient. If decision-making to withhold / withdraw treatment requires the normative context concerning the value of life, it means withholding/withdrawing treatment based on physiological futility defined in chapter 4 is at least ethically disputable, that is, it cannot be by itself a sufficient standard of withholding/withdrawing treatment to neonates with impairment.

Accordingly, an intermediate judgement is required to lead from judgement of medical futility to decision of withholding/withdrawing treatment. In this sense, [5] economic futility, more concretely, the concept called ‘distributive justice of rare medical resources’ or ‘the medical efficiency based on the evaluation of the cost-effectiveness’ becomes very important. Economic futility mediates the gap between fact and value by introducing the normative context of distributive justice and makes it possible to accept withholding/withdrawing futile treatment as ethically justifiable. Therefore, the concept of medical futility becomes complete by unifying economic futility and the most rigorous definition of physiological futility we created in chapter 4.

As Kodama points out, the fact that many people thought that there was a hidden intention to restrain the medical expense in the background of the case of Emilio Gonzalez shows that an economic point of view such as distribution of medical resources and a cost-effectiveness evaluation influence the decision of withholding/withdrawing treatment to neonates with impairment (Kodama [2013:89f]). But because Japan and the United States have remarkably

different concepts of distributive justice regarding medical expenses, we will try to reexamine the way of distributive justice in medicine by considering the situation of pediatrics in Japan today.

Recently, in Japan, the number of low birth weight children has increased because of the increase of high-risk births, such as later-in-life pregnancies<sup>11</sup>. Further, chronic lack of the NICU is caused by the increase of long-term hospitalization; consequently, at least 200~500 incubators of NICU are in short supply and urgently needed; as well, large-scale additional facilities are required<sup>12</sup>. In such situations, long-term hospitalization of neonates of poor convalescence has aggravated the rate of operation of NICU; therefore, the need to restrict treatment to neonates of the poor convalescence has been discussed (Tamura [2005:74f]). According to Kawabata, physicians in Kanagawa Children's Medical Center have asked the parents of neonatal patients in NICU for changing hospital facilities, in order to accept a new neonatal patient, and have carried it out under their agreement (Kawabata [2013:74]).

Under the present conditions of the shortage of NICU, it is practically impossible to give all the neonates with impairment maximum treatment. Therefore, even if some of neonates with impairment cannot receive the maximum treatment, we cannot accuse the facilities of malpractice<sup>13</sup>. But the idea to accept withholding/withdrawing treatment to neonates with impairment, while ignoring the situation of the shortage of NICU, seems to confuse the cause and the effect. Increasing supplies by adding NICUs must be the basic solution, if NICU is in short supply, and the countermeasure to restrain demand is only a temporary remedy.

On the other hand, increase of NICU and the treatment to neonates with impairment is sometimes brought into question from a viewpoint of the distribution of limited medical resources. Kumada points out that an initial expense of 20 million yen is needed to install one NICU. Furthermore, operating one NICU makes at least a deficit of 4.6 million yen a year (Kumada [2010:64f]). In addition, it costs 7~8 million yen on average when an extremely low birth weight child is hospitalized in an NICU, but the self-pay of parents is restrained within a

fixed amount of money by support systems such as "Medical Care Benefits for Premature Babies". These deficits and expenses will be covered with tax and insurance premiums under the Japanese universal health coverage system, but this means most of the medical expenses for neonates are borne by taxpayers and insured persons that have no relationship with those neonates who receive treatment.

The claim to restrict the futile care to neonates with impairment is founded on the opinion that if the society bears most of the medical expenses for neonatology publicly, the fairness of the use of these expenses must be brought into the question. But this claim has a big problem, particularly, why neonates with impairment must be targeted first. Sakurai points out that ICU for adults is much higher in the medical expenses reduction effect than NICU (Sakurai [2015:11]). In fact, according to the survey conducted by Actuarial Research Division of Health Insurance Bureau of MHLW, the medical expenses for preschool children are 1,400 billion yen a year while the medical expenses for elderly persons 75 years or older reach 14,500 billion yen a year<sup>14</sup>. If we reduce 50% of the medical expenses for preschool children, we would save less money than if we reduced only 5% of the medical expenses for elderly persons, so the medical expenses reduction effect is equal to practically nothing, even if we reduce expenses for NICUs accounting for only a small part of the medical expenses for preschool children.

Therefore, the necessity in the medical economy to reduce the expenses for neonatal medical care preferentially in the whole medical expenditures is extremely suspect, and it is certain that argument about medical restriction to neonates with impairment has nothing to do with distributive justice. In fact, many researchers have argued from an ethical point of view that the market mechanism is inappropriate for realization of distributive justice, that market society is basically incompatible with the idea of welfare society, and that morality is spoiled when we entrust the medical care system and the welfare system to the market principle giving top priority to economic efficiency (Mori [2013:122f]).

## 7. Disability studies and the right to live

Since available social resources are in fact limited, we must sometimes accept decisions to exclude someone from their distribution. And when we make such a decision in the name of ‘justice’, it must be based on the social agreement that reflects the general will of the nation. But under the democracy based on the simple decision by majority, intention of the minority always faces the risk of being oppressed. Therefore, it becomes the important problem in modern societies how to reflect the intention of minority people in the collective decision-making and how to protect their rights. Since neonates born with impairment are indeed a minority in our society, decision-making regarding withholding/withdrawing their treatment should reflect their interests as well. That is, if we can justify withdrawing / withholding treatment to neonates with impairment, the decision must be supported by a broad consensus of society.

However, neonates with impairment have no way to express their own interests. We need to establish the system that allows those who can speak for neonates’ rights and interests (such as researchers in disability studies or representatives from groups of impaired persons) in decision-making, as neonates’ best advocates. Then we can also make an ethical ‘defensive wall’ to avoid the medical discrimination by reason of disability. Such an attempt to promote participation in decision-making of the persons concerned confirms the idea of disability studies: “Nothing about us without us”<sup>15</sup>.

We have great precedents about the participation of impaired persons in political decision-making. The Union of the Physically Impaired Against Segregation (UPIAS) in the U.K. supports the “Convention on the Rights of Persons with Disabilities (following CRPD)”, which was adopted in the United Nations General Assembly, in 2006. As well, in the United States, many groups of impaired persons have played a significant role in the establishment of “Americans with Disabilities Act of 1990” (Goodly [2011:3f]).

In Japan, however, we must pay attention to the fact that Japan could not ratify CRPD until 2014 (140th in the world), due to Japan’s poor

maintenance and development of civil law, and the fact that activities of Japanese administration are often criticized that they give priority to financial burden reduction over promotion of the social participation and independence of persons with impairment (Teramoto [2014:242f]). Establishing a public system that can reflect the intention of impaired persons in the place of policymaking is an urgent issue in Japan<sup>16</sup>.

Disability studies theoretically support the promotion of participation of persons with impairment in political decision-making. One of the biggest characteristics of disability studies is distinction between ‘impairment’ and ‘disability’. While impairment is defined as the lack or the loss of mind and body or its functions, disability is defined as “a problem of the social suppression for the human being with impairment” (Ishikawa [1999:15]). And another big characteristic is led from here; the switch from “the personal model” to “the social model” (Ishikawa [2002:23]). Whereas the personal model put the cause and responsibility for disability on individuals, the social model claims that the society is to blame for disadvantages that persons with impairment are forced to endure and points out that the root of the problem lies in the sense of discrimination of people without impairment and the social system obstructing the social participation or the independence of persons with impairment. More precisely, disability studies reinterpret the structure of ‘disability’ as responsibility of the whole society to address situations that persons with impairment are forced to experience various disadvantages.

The claim of this paper can get a stronger basis by learning from disability studies. For example, the importance of social context accords with the issue of disability studies that propose the switch from the personal model to the social model. And being founded on the social model makes it possible to reconsider the issue of withholding/withdrawing treatment to neonates with impairment within the social context and to ethically criticize it as an example of social deprivation. Besides, considering that the personal model is called “the medical model”, because the personal model tries to relieve or improve impairments medically, the switch from the personal model to the social model also leads to the switch from the medical model at the



same time. Doing so enables us to reinterpret the problem of withholding/withdrawing treatment to neonates with impairment not as the exclusive decision matter of physicians, but as a matter that the whole society should undertake<sup>17</sup>.

Yet we can never forget that many researchers in disability studies and advocates of disability groups show the deep distrust of some bioethicists whose claims seem as if their views accord with eugenic thought (Ouellette [2011:29,68]). Also in Japan, as Hiroshi Yokota, a former president of the National Green Grass Association, has strongly criticized that the Japanese welfare system is not working for promoting their rights, but rather for excluding them from society, the distrust of the “logic of people without impairment” (Yokota [2015:37]) is deep-rooted. That is why people without impairment must learn humbly from disability studies with “a viewpoint not to deny impairments” (Ogawa [2014:169]).

## 8. Conclusion

Since the right to live is one of the fundamental human rights and therefore should be guaranteed to every human being, according to the principle of equality, the restriction of medical care to neonates with impairment is an infringement to their right to live, unless the available medical resources are in fact in short supply.

The issue of withholding/withdrawing treatment to those who are in the weakest position in society reflects the cultural maturity or ethical sincerity of Japanese society that can attach greater importance to the rights of the weak than economic efficiency. Therefore, the ethically valid manner we should take is to construct ‘a society respecting human life’ based on mutual understanding and approval between persons with impairment and persons without impairment. In other words, making maximum efforts for symbiosis and inclusion, not for exclusion, is the right path we should choose.

## Notes

- 1 In this paper, we use this term in the sense that Beauchamp and Childress defined in their famous work (Beauchamp [1979]).
- 2 The Yomiuri Shimbun, October 21, 2013.
- 3 The meaning of the term ‘death with dignity’ is not necessarily clear, as the concept means physician-assisted suicide in the USA. However, this present article uses this ‘death with dignity’ concept in the context of ‘withholding/withdrawing of life-prolonging treatment’.
- 4 The official name of this law is “Deutsche Betreuungsrecht”. In its third revision, the advance directive of the patients was legalized.
- 5 See Colby [2006] about the importance of self-determination for terminal care.
- 6 The Mainichi Shimbun, March 27, 2015.
- 7 See Foot [1977:109].
- 8 Cohen insists that we should judge carefully whether there is a conflict of interests between parents and neonates with impairment based on “a system of child agents” (Cohen [1980:75]), yet the doubt is inevitable concerning who is qualified to be a person of judgement. Weir proposes “a serial ordering of decision makers”, which shifts from a lower proxy to a higher one (Weir[1984:268f]), but it is doubtful whether this method can function enough in Japan because there are very few Hospital Ethics Committees in Japan, in contrast to the USA (Kubota [2014:97f]).
- 9 Virginia and California have adopted a law similar to TADA.
- 10 This rigorous interpretation of medical futility is an original definition by the author.
- 11 See “The problem and solution of neonatology: The present conditions called the deficiency in NICU and neonatologists” (materials for Japanese Neonatologist Association in November 25, 2008), p.4 (In Japanese).
- 12 See “The problem and solution of neonatology: The present conditions called the deficiency in NICU and neonatologists”, p.8-9 (In Japanese).
- 13 See Mori [2015:16].
- 14 See “The Trend of Medical Care Expenditures 2014”.
- 15 See Ogawa [2014:25] about this phrase.
- 16 It is the first step to achieve the broad consensus mentioned above, not the goal.
- 17 See Goodly [2011:8] concerning the criticism to entrusting the issue of impaired persons to medicine.

## References

- Beauchamp, T. et al., 1979: *Principles of Biomedical Ethics*, Oxford University Press.
- Duff, R.S. et al., 1973: “Moral and Ethical Dilemmas in the Special-Care Nursery”, *The New England Journal of Medicine* 289, pp.890-894.
- Sawano, K., 2012: “France - agreement in the medical

- care and protection of the minor”, *The Medical Care of Children and the Law*, (ed. Koyama. et al.), p.262-301, (In Japanese).
- Koyama, T. et al. (ed.), 2012: *The Medical Care of Children and the Law* (2<sup>nd</sup>. Edition), Shogakusya, (In Japanese).
- Tamai, M., 1996: “Pediatrics and the informed consent - from the standpoint of patient family”, *Neonatal Care* 9(6), p.492-497, (In Japanese).
- Nishida, H. et al., 1986: “Medical decision-making from ethical point of view in Pediatrics”, *Acta Neonatologica Japonica* 23(1), p.337-341, (In Japanese).
- Tamura, M. et al. (ed.), 2005: *Bioethics in the Field of Neonatal Care; Concerning the “Guidelines for Healthcare Providers and Parents”*, Medicus Shuppan, (In Japanese).
- Weir, R.S., 1984: *Selective Nontreatment of Handicapped Newborns*, Oxford University Press.
- American Medical Association, Council on Ethical and Juridical Affairs, 1994: “Code of Medical Ethics E-2.215 Treatment Decision for Seriously Ill Newborns”.
- Ouellette, A., 2011: *Bioethics and Disability - Toward a Disability-Conscious Bioethics*, Cambridge University Press.
- Krones, T. et al., 2013: “Medical futility from the Swiss perspective”, *Medical Futility: A Cross-National Study*, (ed. Bagheri, A.), Imperial College Press, p.205-226.
- Brody, B.A. et al., 1995: “Is futility a futile concept?”, *Journal of Medicine and Philosophy* 20, p.123-144.
- Bernheim, J.L. et al., 2013: “Medical futility and end-of-life issues in Belgium”, *Medical Futility: A Cross-National Study*, (ed. Bagheri, A.), Imperial College Press, p.59-83.
- Schneiderman, L. et al., 1995: *Wrong Medicine, Doctors, Patients, and Futile Treatment*, Johns Hopkins University Press.
- Brody, H., 1997: “Medical futility: a useful concept?”, *Medical Futility*, (ed. Zucker, M. B. et al.), Cambridge University Press, p.1-14.
- Schneiderman, L. et al., 1990: “Medical futility: its meaning and ethical implications”, *Annals of Internal Medicine* 112, p.949-954.
- Werth, J.L., 2005: “Concerns about decisions related to withholding/withdrawing life-sustain treatment and futility for persons with disabilities”, *Journal of Disability Policy Studies* 16, p.31-37.
- Wall, S.N. et al., 1997: “Death in the Intensive Care Nursery: Physician Practice of Withholding Life Support”, *Pediatrics* 99(1), p. 64-70.
- Prip, W. et al., 1997: “Medical futility: a legal perspective”, *Medical Futility*, (ed. Zucker, M. B. et al.), Cambridge University Press, p.136-154.
- Veatch, R.M., 2013: “So-called futile care: the experience of the United States”, *Medical Futility: A Cross-National Study*, (ed. Bagheri, A.), Imperial College Press, p.9-33.
- Halliday, R., 1997: “Medical futility and the social context”, *Journal of Medical Ethics* 23, p.148-153.
- Katz, M., 2011: “When is medical care ‘futile’? The institutional competence of the medical profession regarding the provision of life-sustaining medical care”, *Nebraska Law Review* 90: 1.
- Kodama, M., 2013: *Destination of Self-Decision Right of Death, Death with dignity, Futile care debate, Organ transplant*, Otsukishoten, (In Japanese).
- Kawabata, E., 2013: *End-of-life-care for My Very Little Child*, Kobunsha, (In Japanese).
- Kumada, R., 2010: *Those Who Save Children: To what extent do you require for medicine?*, Lohasmedia, (In Japanese).
- Sakurai, H. et al., 2015: “A discussion of medical futility in neonatal care”, *Journal of Clinical Ethics*, No.3, p.7-15, (In Japanese).
- Mori, Y., 2013: “The market economy and bioethics”, *The Japanese Bioethics Series 20: Frontier of Bioethics*, Maruzen Publishing, p.115-132, (In Japanese).
- Mori, Y., 2015: “Ethical validity of withholding treatment to neonates born with congenital diseases”, *Annals of the Japanese Association for Philosophical and Ethical Researches in Medicine*, vol.33, p.10-20, (In Japanese).
- Goodly, D., 2011: *Disability Studies, An Interdisciplinary Introduction*, Sage.
- Teramoto, A. et al., 2015: *Support Not According with Demand*, Seikatsushoin, (In Japanese).
- Ishikawa, J. et al. (ed.), 1999: *An Invitation to Disability Studies*, Akashishoten, (In Japanese).
- Ishikawa, J. et al. (ed.), 2002: *The Claim of Disability Studies*, Akashishoten, (In Japanese).
- Yokota, H., 2015: *The Thought of Murdering Disabled Persons* (new & enlarged edition), Gendaishokan, (In Japanese).
- Ogawa, Y. et al. (ed.), 2014: *Disability Studies Easy to Understand*, Minervashobo, (In Japanese).
- Colby, W.H., 2006: *Unplugged: Reclaiming Our Right to Die in America*, AMACOM.
- Foot, P., 1977: “Euthanasia”, *Philosophy and Public Affairs* 6, pp.85-112.
- Cohen, H., 1980: *Equal Rights for Children*, Littlefield, Adams & Co.
- Weir, R.S., 1984: *Selective Nontreatment of Handicapped Newborns*, Oxford University Press.
- Kubota, A. et al., 2014: *An Introduction to Perinatal Care and Bioethics*, Medicus Syuppan, (In Japanese).