

# International Comparison of Physicians' Attitudes Toward Refusal of Treatment by Patients with Severe Anorexia Nervosa: A Case-Based Vignette Study

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## Research Article

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# Abstract

**Background:** We investigated the attitudes of physicians in Japan, the United Kingdom (UK), and the United States (US) toward refusal of treatment for anorexia nervosa.

**Methods:** A questionnaire survey was administered to eating disorder physicians (Japan, n=55; UK, n=84; US, n=82) to evaluate their treatment strategies for fictitious cases of refusal of treatment for anorexia nervosa.

**Results:** For acute patients, 53 (96.3%) physicians in Japan, 65 (77.4%) in the UK, and 54 (65.9%) in the US chose compulsory treatment if the patient's family requested treatment, while 46 (83.6%) physicians in Japan, 53 (63.1%) in the UK, and 47 (57.3%) in the US chose compulsory treatment if the family left the decision to the patient. For severe and enduring patients, 53 (96.3%) physicians in Japan, 62 (73.8%) in the UK, and 57 (69.5%) in the US chose compulsory treatment if the patient's family requested treatment, while 38 (69.1%) physicians in Japan, 56 (66.7%) in the UK, and 55 (67.1%) in the US chose compulsory treatment if the family left the decision to the patient.

**Conclusions:** Physicians in all three countries tended to choose compulsory treatment irrespective of disease duration or whether the patient's family requested treatment or not. This may indicate that medical practitioners value the ethical obligation of beneficence, giving priority to the protection of life. Attitudes toward refusal of treatment during a life crisis tend to vary among medical professionals, particularly if the patient's family does not request treatment.

## Plain English Summary

We conducted this study to investigate the attitudes of physicians in Japan, the UK, and the US toward refusal of treatment for AN. This study revealed that in Japan, the US, and the UK, compulsory treatment tends to be the prevalent choice in cases of life-threatening malnutrition, regardless of the patient's age or duration of illness. Compulsory treatment was chosen more often when family members requested treatment than when family members left the decision to the individual. The results also indicated a significant difference in the tendency to choose compulsory treatment among physicians in the three countries.

## Background

A challenge regarding the treatment of eating disorders is the refusal of treatment [1]. Obtaining informed consent from the patient is a prerequisite for performing some therapeutic actions. Therefore, refusal of treatment by patients with eating disorders hampers treatment initiation. Particularly, refusal of treatment by low-weight patients with anorexia nervosa (AN) who need urgent medical treatment makes the management of such cases challenging. Compulsory treatment needed to save a patient's life regardless of the patient's wishes entails ethical concerns. If a patient refuses treatment even when it is necessary, prioritizing the protection of life would infringe the patient's self-determination. There have been legal

disputes and ethical debates on whether coercive treatment should be administered to patients with AN who refuse treatment. However, there are currently no guidelines or definitive opinions on the subject.

In Japan, the United Kingdom (UK), and the United States (US), patients with mental disorders who are at risk of self-injury or other harm can be legally and forcibly hospitalized if they do not consent to inpatient treatment. In Japan, a system of hospitalization for medical protection allows treatment to be administered to a patient who is not in a condition to consent to treatment, even if there is no fear of self-injury or other harm; however, this is only done with the consent of the patient's guardian. This system of hospitalization for medical protection is different from that in Western countries, which emphasize the patient's right to self-determination as represented by the requirement for informed consent.

The attitudes of medical professionals toward refusal of treatment by patients with AN may possibly differ between Japan, the US, and Europe due to differences in cultural and legal backgrounds. Various opinions have been expressed from the perspective of law and medical ethics regarding compulsory treatment for patients with AN who refuse treatment [2]. Furthermore, what physicians consider important and what attitudes they adopt when managing refusal of care by patients with life-threatening AN is unclear. Thus, this study aimed to evaluate the attitudes of expert physicians in the UK, the US, and Japan on refusal of treatment by patients with AN.

## Methods

We conducted an anonymous self-administered questionnaire survey delivered by mail to 212 members of the Japanese Society for Eating Disorders. For comparison, an anonymous web-based questionnaire with similar questions created by the double translation was administered to eating disorder specialists in the US and the UK. In the US, a web-based survey was conducted among physicians registered with MD.Linx (more than 415,000 doctors in total) who are members of eating disorder-related societies such as the Academy of Eating Disorder and who practice eating disorder treatment. In the UK, a web-based survey was conducted among doctors registered with Doctors.net.uk (over 200,000 doctors in total) who are members of eating disorder-related societies such as the British Eating Disorder Academy and who practice eating disorder treatment. The web survey was conducted through a survey company that solicited responses until more than 80 responses were collected, assuming the maximum response rate in Japan was 40%. In both the US and the UK, three announcements encouraging cooperation in the survey were made over a six-week period.

Four fictitious vignette cases were used in the study, each consisting of a combination of two different patient conditions (Case A and B) and the reactions of two different patients' families, and the respondents were asked whether they would choose compulsory inpatient treatment or not (see Appendix).

## Statistical analysis

We used the  $\chi^2$  test to examine whether there were differences in the responses from physicians in the three countries. If the  $\chi^2$  test result was significant, the  $\chi^2$  test or Fisher's direct method was used to analyze the differences in the responses between two countries and Bonferroni's correction was made.  $p < 0.01$  was considered statistically significant.

The McNemar's test was used to test the tendency of individual responses by physicians in each country to change between Case A and Case B, and to test whether the individual responses changed depending on request for treatment by the patient's family or not.

For each country, kappa coefficients were calculated to test the tendency of individual responses to change between Case A and Case B, and to test whether the tendency of individual responses to change depending on whether the patient's family wanted to be involved in the case or not. All analyses were two-tailed and a  $p$  value  $< 0.05$  was considered statistically significant.

## **Ethical considerations**

This study was approved by the Ethics Committee of the Faculty of Medicine, The University of Tokyo (No. 3938-1).

## **Results**

### **General characteristics of the respondents**

Fifty-five valid responses were obtained from physicians in Japan who specialize in treating eating disorders (25.9% response rate). The physicians included 21 psychosomatic physicians, 24 psychiatrists, and 10 adolescent medicine physicians. Psychosomatic physicians are trained in internal medicine with additional psychiatric-psychosomatic training and both psychosomatic physician and psychiatrist mainly treat eating disorders in Japan. Most physicians had 10 to 19 years of experience, while some had more than 30 years of experience. Most physicians treated 50 to 99 patients in a year, while some treated 150 to 199 patients in a year (Table 1).

Table 1  
Characteristics of subjects

Years of experience as a clinician							
	< 5 years	5–9 years	10–19 years	20–29 years	> 30 years		
Japan (n = 55)	0	8	19	12	16		
UK (n = 84)	2	8	50	18	6		
US (n = 82)	4	17	36	20	5		
Number of AN patients examined in a year							
	< 20 patients	20–49 patients	50–99 patient	100–149 patients	150–199 patients	200–299 patients	> 300 patients
Japan (n = 55)	0	8	19	12	16	0	0
UK (n = 84)	0	46	21	8	2	3	4
US (n = 82)	0	0	41	22	4	8	7
UK, United Kingdom; US, United States of America; AN, anorexia nervosa							

Eighty-four valid responses were obtained from the UK. All respondents were psychiatrists. Of the physicians who responded, 28.2% worked in clinics that specialized in treating eating disorders, 24.7% worked in hospitals that specialized in treating eating disorders, and 57.0% worked in other medical facilities. Most physicians had 10 to 19 years of experience, while some had 20 to 29 years of experience. Most physicians treated 20 to 49 patients for eating disorders per year, while some treated 50 to 99 per year.

Eighty-one valid responses were obtained from the US. All respondents were psychiatrists. Of the physicians who responded, 44.7% worked in clinics that specialized in treating eating disorders, 16.5% worked in hospitals that specialized in treating eating disorders, and 38.8% worked in other medical facilities. Most physicians had 10 to 19 years of experience, while some had 20 to 29 years of experience. Most physicians treated 50 to 99 patients per year, while some treated 100 to 149 patients per year.

The number of samples required for statistical analysis was 90, and this value was calculated by setting the difference at 40 points in accordance with previous studies [3], with  $\alpha = 0.05$  and  $\beta = 0.1$ .

## Comparison of responses from Japan, the US, and the UK

For young patients with acute AN, 53 (96%) physicians in Japan, 65 (77%) in the UK, and 54 (66%) in the US indicated that they would choose compulsory inpatient treatment if the patient's family requested treatment. There was a significant bias in the response rates of the three countries. Bilateral comparison showed significant differences between the responses from Japan and from the UK ( $p = 0.003$ ) and between those from Japan and from the US ( $p = 1.3 \times 10^{-4}$ ) (Table 2). Forty-six (84%) physicians in Japan, 53 (63%) in the UK, and 47 (57%) in the US responded that they would choose compulsory inpatient treatment if the patient's family left the decision to the patient. Additionally, there was a significant bias in the response rates of the three countries. Bilateral comparison showed that there was a significant difference between the responses from Japan and from the UK and between the responses from Japan and from the US (Table 2).

Table 2  
Responses from Japan, the US, and the UK

		Acute patients with AN			Severe and enduring patients with AN		
		Patient's family requested treatment	Patient's family did not request treatment	McNemar's test P-value	Patient's family requested treatment	Patient's family did not request treatment	McNemar's test P-value
Japan (n = 55)	CT	53 (96%) <sup>ab</sup>	46 (84%) <sup>cd</sup>	$p = .125$	53 (96%) <sup>ef</sup>	38 (69%)	$p = 1.2 \times 10^{-4}$
	RW	2 (4%)	9 (16%)		2 (4%)	17 (31%)	
UK (n = 84)	CT	65 (77%) <sup>a</sup>	53 (63%) <sup>c</sup>	$p = .001$	62 (74%) <sup>e</sup>	56 (67%)	$p = .063$
	RW	19 (23%)	31 (37%)		22 (26%)	28 (33%)	
US (n = 82)	CT	54 (66%) <sup>b</sup>	47 (57%) <sup>d</sup>	$p = .022$	57 (69%) <sup>f</sup>	55 (67%)	$p = .022$
	RW	28 (34%)	35 (43%)		25 (31%)	27 (33%)	
$\chi^2$ test P value		$\chi^2 = 16.987$ ; df = 2; $p = 2.1 \times 10^{-4}$	$\chi^2 = 14.656$ ; df = 2; $p = .005$		$\chi^2 = 16.556$ ; df = 2; $p = .002$	$\chi^2(2) = 0.565$ ; df = 2; $p = .754$	
IT, choice of compulsory inpatient treatment; RW, respect for patient's wishes; UK, United Kingdom; US, United States of America.							
<sup>a</sup> $p = .003$ by Fisher's exact test, <sup>b</sup> $p = 1.3 \times 10^{-4}$ by Fisher's exact test, <sup>c</sup> $p = .008$ by $\chi^2 = 16.987$ ; df = 1, <sup>d</sup> $p = 4.9 \times 10^{-4}$ by Fisher's exact test, <sup>e</sup> $p = .001$ , Fisher's exact test, <sup>f</sup> $p = 4.9 \times 10^{-4}$ by $\chi^2 = 15.703$ ; df = 1.							

For elderly patients with severe and enduring AN, 53 (96%) physicians in Japan, 62 (74%) in the UK, and 57 (70%) in the US indicated that they would choose compulsory inpatient treatment if the patient's family wanted to initiate treatment. There was a significant bias in the response rates of the three countries. Bilateral comparison showed that there was a significant difference between the responses from Japan and from the UK and between those from Japan and from the US. Thirty-eight (69%) physicians in Japan, 56 (66%) in the UK, and 55 (67%) in the US responded that they would choose compulsory inpatient treatment if the patient's family left the decision to receive treatment to the patient. There was no significant bias in response rates among the three countries.

## **Comparison of response trends in each country**

For young patients with acute AN, there was no difference between the tendency for individual physicians in Japan to choose compulsory treatment if the patient's family wanted to initiate treatment and the tendency for them to choose compulsory treatment if the family left the decision to the patient. However, there was a significant difference in the propensity of physicians in the UK and in the US to choose compulsory treatment (Table 2).

For elderly patients with severe and enduring AN, there was a significant difference between the tendency for individual physicians in Japan to choose compulsory treatment if the patient's family wanted to initiate treatment and the tendency for them to choose compulsory treatment if the family left the decision to the patient. However, there was no significant difference in the tendency for physicians in the UK and in the US to choose compulsory treatment.

There was no significant difference between the choices of physicians for young and older patients if family members requested treatment. Likewise, there was no significant difference between the choices of physicians for young and older patients if the patient's family members left the decision to receive treatment to the patient.

## **Comparison based on years of physician experience and number of case experiences**

Whether attitudes differed by years of experience and the number of cases treated among physicians in the UK and the US, where trends are similar, was examined. No significant differences in attitudes were found between physicians with more than 20 years of experience and those with less than 10 years of experience. There was no significant difference in attitude between physicians who saw more than 100 cases per year and those who saw less than 30 cases per year (Table 3).

Table 3

Differences in attitudes based on years of physician experience and number of case experiences

		Acute patients with AN		Severe and enduring patients with AN	
		Patient's family requested treatment	Patient's family did not request treatment	Patient's family requested treatment	Patient's family did not request treatment
Physicians with less than 10 years of experience (n = 30)	CT	21 (70%)	21 (70%)	17 (57%)	17 (57%)
	RW	9 (30%)	9 (30%)	13 (43%)	13 (43%)
Physicians with at least 20 years of experience (n = 49)	CT	34 (69%)	30 (61%)	36 (73%)	37 (76%)
	RW	15 (31%)	19 (39%)	13 (27%)	12 (24%)
Fisher's exact test P value		p = 1.00	p = .476	p = .144	p = .089
Physicians treating less than 30 cases of patients with AN per year (n = 37)	CT	29 (78%)	22 (59%)	28 (76%) <sup>f</sup>	24 (65%)
	RW	8 (22%)	15 (41%)	9 (24%)	13 (35%)
Physicians treating more than 100 cases of patients with AN per year (n = 57)	CT	38 (67%)	36 (63%)	40 (70%)	40 (70%)
	RW	19 (33%)	21 (37%)	17 (30%)	17 (30%)
Fisher's exact test P value		p = .251	p = .829	p = .641	p = .653

IT, choice of compulsory inpatient treatment; RW, respect for patient's wishes

## Discussion

We conducted this study to investigate the attitudes of physicians in Japan, the UK, and the US toward refusal of treatment for AN. To our knowledge, this is the first report of an international investigation on the propensity of physicians to choose compulsory treatment in cases of refusal of treatment for eating disorders. This study revealed that in Japan, the US, and the UK, compulsory treatment tends to be the prevalent choice in cases of life-threatening malnutrition, regardless of the patient's age or duration of illness. Compulsory treatment was chosen more often when family members requested treatment than when family members left the decision to the individual. The results also indicated a significant difference in the tendency to choose compulsory treatment among physicians in the three countries.

Refusal of treatment in life-threatening cases of malnutrition poses the ethical dilemma of whether the physician should prioritize the protection of the patient's life or the patient's right to self-determination [4].

From the perspective of the four principles of medical ethics [5], it can be analyzed as an ethical issue of comparative consideration between the principle of good conduct and the principle of respect for autonomy. In the present study, physicians from Japan, the UK, and the US often chose the policy of compulsory treatment in life-threatening cases of poor nutrition, regardless of the patient's intention. The background of this attitude seems to be the idea of prioritizing the protection of life as the medical interest of the patient; that is, prioritizing the ethical obligation of beneficence over the ethical obligation of respect for autonomy. This idea has been reported in several articles on ethical considerations in cases of treatment refusal [6].

There is no consensus on whether patients with AN are able to make decisions regarding treatment [7, 8]. However, one reason that the duty of beneficence may take precedence over the patient's self-determination is the presumption that patients with AN who are undernourished are not in a condition to make sound decisions [9, 10]. In a situation where the patient cannot make appropriate decisions, it is common for family members to speculate on the patient's wishes on behalf of the patient. In fact, the responses in the present study indicated a greater tendency for selection of compulsory treatment when the patient's family wanted treatment than when they did not. This may be because the medical practitioner believes the patient is not competent enough to make sound decisions, and therefore follows the opinion of a family member who is the surrogate estimator. Conversely, over half of the physicians in Japan, the UK, and the US responded that they would choose compulsory treatment even if the patient's family did not wish to initiate it. It is probable that in such situations, the patient's family did not consider the patient's best interest to be a priority, and the medical care provider considered the patient's best interest to be the protection of life. Regarding the refusal of treatment by patients experiencing life crises, Giordano [11] advocated for "legitimate use of prudence, recognition of the value of life, and common sense" and stated that "if there is a fairly good chance that the patient will thank you for rescuing her, then you should rescue her." It has been reported that although patients with AN may refuse treatment, they are glad to have received coercive treatment after recovery [12]. It could be said that this is a strong form of paternalism [13].

The possibility that cognitive and affective biases might influence clinicians' decision-making in cases of patient with AN refusal of treatment cannot be ignored [14]. For example, self-serving concerns about the reputation of their peers and colleagues for the decisions they make may lead many physicians to be very conservative in their clinical decisions. Concerns about being sued for negligence may also be a factor in their choice to make conservative decisions (especially in the US).

In the present study, the proportion of physicians who preferred involuntary treatment was significantly higher in Japan than in the US and the UK. This may be due in part to the fact that awareness of patient self-determination occurred late in Japan [15] and attitudes are more paternalistic, emphasizing the ethical obligation of beneficence [16]. Moreover, Japanese law makes it easier to provide inpatient treatment when a patient refuses treatment despite having life-threatening malnutrition. In Japan, a person who is not in a condition to be hospitalized voluntarily, even if there is no risk of self-injury or other harm, can be hospitalized after examination by a doctor and with family consent. The tendency for a

patient's family to influence the treatment plan in Japanese medicine has been reported previously [3]. Japanese culture is more family-centered than the more individualistic British and American cultures, and this may be another reason why the choice of compulsory treatment is prevalent in Japan, particularly if the patient's family members request treatment.

In the present study, the number of physicians who chose compulsory treatment for young patients was significantly lower when the decision was left to the patient than when the patient's family wanted to initiate treatment in the UK and the US. The reason for this may be that if the decision to initiate treatment is left to the patient, compulsory treatment may break down the therapeutic relationship and make it difficult to continue treatment in the future. Although young patients with acute disease are less likely to be in mortal danger than are older patients, ensuring that treatment can be continued may be in their best interest. In fact, it has been reported that compulsory hospitalization may only have a limited therapeutic effect [17].

The difference between Cases A and B was the age of the patient and the duration of the disease. Case B was more severe because of the longer duration of the disease. Although it has been reported that some patients appreciate having received coercive treatment after recovery [12], some severely ill patients have been reported to oppose coercive treatment even after they have recovered [18]. For patients with severe AN with a long disease duration, the long-lasting fear of obesity may have been pathologically internalized as an identity; thus, refusing treatment may have reached the point of being a belief for the patients. In the present study, the proportion of physicians in all three countries who did not choose compulsory treatment for older patients with long disease duration was higher than that of physicians who did not choose compulsory treatment for younger patients. This trend was also noted in the choices of physicians if family members left the decision to receive treatment to the patient; however, the result was not statistically significant. This trend may indicate that in the case of severe and enduring patients with long disease duration, their morbid attitudes may have been interpreted as beliefs related to their identities, and as a result, physicians may have respected the patient's self-determination. Furthermore, even if a life-threatening AN crisis is averted for patients with severe and enduring disease, the crisis is likely to recur [19]. This may be a reason why some respondents in the present study considered involuntary treatment to be futile from a long-term perspective.

In the UK and the US, where trends are relatively similar, we examined attitudes toward refusal of treatment among physicians with more or less years of experience as clinicians, and among physicians who saw more or fewer patients, and found no significant differences. Attitudes toward refusal of treatment reflect ethical values, and these results may suggest that these values may be in place from the beginning in each physician as an individual, rather than being developed by their experience as physicians.

## **Strengths and Limitations**

Ethical issues in clinical practice are difficult to solve with normative theory alone. When responding normatively to ethical issues in clinical practice, it is important to consider what should be done after understanding the current situation through empirical data. This is the first international survey of physicians' attitudes toward refusal to treat patients with AN and the data presented here could be used as reference when considering treatment refusal in patients with AN from the perspective of empirical bioethics [20]. This study has some limitations. First, the attitude toward a fictitious vignette case may differ from the attitude when confronted with an actual case of refusal of treatment in the course of clinical practice due to mental conflict. Second, since it was conducted using simulated cases, the effect of the inpatient facilities and ethics policies from the respondents' institutions on their individual responses is unknown. Third, owing to the small size of the study sample, the generalizability of the survey is difficult to estimate. Fourth, since the survey was conducted using questionnaires delivered by mail in Japan, but web-based questionnaires were used instead in the UK and in the US, it is possible that differences in the survey method may have affected the results. Fifth, although a dual translation was used, the translation of the vignette cases may have altered some nuances and therefore potentially biased the responses. Despite these limitations, this study is significant in that it is the first international survey conducted to compare the attitudes of medical practitioners toward refusal of treatment by patients with eating disorders.

In the future, it will be necessary to investigate whether physicians in practice recognize the mental capacity of patients with severe AN, what they emphasize in assessing mental capacity, what specific treatment they provide after choosing compulsory treatment, and what type of treatment is provided when compulsory treatment is not chosen.

## Conclusions

Ideally, the response to refusal of treatment by patients with AN should be to protect life while respecting the patient's autonomy from an ethical standpoint. However, how this balance should be struck is not clear. The present study revealed that the attitudes and choices of physicians regarding refusal of treatment for eating disorders tend to vary, particularly if the patient's family members left the decision to receive treatment to the patient. Since the patient's condition and surrounding circumstances differ from case to case, it is difficult to determine a uniform response in advance. It may be useful to develop guidelines for shareable broad ethical ideas and decision-making procedures. Keeping the decision-making process uniform and fair, through guidelines, would satisfy procedural justice [21]. However, as can be seen from the differences in the attitudes of physicians in each country revealed in the present study, it is important to consider the background of each country while ensuring that the important ethical arguments are included in the guidelines. This is because guidelines based just on ethical idealism will be confusing in actual clinical practice.

## Abbreviations

United Kingdom (UK)

United States (US)

anorexia nervosa (AN)

## Declarations

### *Ethics approval and consent to participate*

This study was approved by the Ethics Committee of the Faculty of Medicine, The University of Tokyo (No. 3938-1). All subjects provided consent to participate in the study.

### *Consent for publication*

All subjects provided consent to have their data published.

### *Availability of data and materials*

The data that supports the findings of this study are available from the corresponding author on reasonable request.

### *Competing interests*

The authors declare that they have no competing interests.

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### *Authors' contributions*

I, Yoshiyuki Takimoto, contributed to the study conception, design, data collection and analysis, and wrote the manuscript.

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