Eating or Treating?: Legal and Bioethical Issues Surrounding Anorexia Nervosa

YEMEK Mİ?-TEDAVİ Mi?: ANOREXIA NERVOSA'YI ÇEVRELEYEN HUKUKİ VE BİYOETİK KONULAR

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Summary

Disclosing difficulties, posing the best questions, is one of the most important and difficult tasks of philosophy. This article highlights the legal, conceptual and ethical difficulties relating to the refusal of treatment for anorexia nervosa. In England, the case of anorexia nervosa has appeared before the courts, and has given rise to peculiar legal and moral issues. Due to the spread of the disorder also in non-European countries, it is likely that similar issues will also arise in other parts of the world. Therefore, the English experience is reported, as it may help anticipating Segal and related ethical problems relating to anorexia nervosa. A part of these issues seems to be linked to the fact that refusing treatment for anorexia nervosa sometimes means refusing a life-saving treatment. This sets the issue of consent to or refusal of treatment at the boundary between informed consent and ending-life decisions. Therefore, a number of problems, terminological, conceptual, and ethical in nature, surrounding ending-life, arise in the case of anorexia nervosa. In this article, these problems are highlighted.

Key Words: Anorexia nervosa, Consent to treatment, Ending-life decisions

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Sometimes the task of philosophy, rather than finding answers, is raising problems. Disclosing difficulties, posing the best questions, is not always easy. (1) In this article, rather than providing normative proposals, I shall raise questions.

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Özet—

Sorunları ortaya koymak, en iyi soruları sorabilmek felsefenin en önemli ve zor görevlerinden birisidir. Bu makale anorexia nervosa'da tedavinin reddedilmesine ilişkin hukuki, kavramsal ve etik sorunlara dikkat çekmektedir. İngiltere'de anoreksia nervosa vakaları mahkemelere intikal etmekte, ve son derece kendine özgü durumlar ortaya çıkmaktadır Rahatsızlığın Avrupa'nın dışında kalan ülkelerde de yaygın olmasından dolayı, aynı konular dünyanın diğer bölgelerinde de ortaya çıkacaktır. Bu yüzden, anoreksia nervosa ile ilgili hukuki ve etik sorunlara hazırlıklı olma konusunda yardımcı olacağı düsüncesiyle İngiltere'deki tecrübeler sunulmustur. Bu sorunların bir kısmı, anoreksia nervosa tedavisini reddetmenin bazen vasam kurtarıcı bir tedaviyi reddetmek anlamına gelmesi anlamına gelmesiyle ilişkilidir. Bu, tedayiyi kabul etme yeva reddetmeyi, aydınlatılmış onanı ve yaşamın sonlandırılması kararının kesiştiği noktaya koymaktadır. Bu yüzden, anoreksia nervosa vakalarında terminolojik, kavramsal ve etik doğaya sahip bir çok konu yaşamın sonlandırılması kararını çevrelemektedir. Bu makalede bu konulara dikkat çekilmektedir

Anahtar Kelimeler: Anorexia nervosa, Tedaviye rıza, Yaşamın sonlandırılması kararı

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My questions will be about a problem which is unfortunately becoming more and more common, especially, but not exclusively, in Western societies, and which has, for the seriousness(2) of physical and psychological complications, and for the speed of its spread, been called a "social epidemic"(3): namely, anorexia nervosa.

In England, the case of anorexia nervosa has appeared before the courts, and has given rise to peculiar legal issues. The general problem has been whether or not it might be right to impose treatment for anorexia nervosa. Since the rapid spread of the disorder concerns also non-European countries(4),

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it is likely that similar questions will also arise in other parts of the world. The English experience may allow anticipating legal and related ethical problems which may arise in the case of refusal of treatment for anorexia nervosa. Therefore, an overview of English legal provisions should be of a general interest.

1§ Legal issues relating to anorexia nervosa

The English law considers anorexia nervosa to be a mental disorder(5). This statement has a precise clinical and legal relevance, since in England(6) a special statute regulating the assessment and treatment of people suffering from mental disorders is in force, that is, the Mental Health Act 1983 (MHA).

Those who suffer from mental illness, mental impairment, severe mental impairment and psychopathic disorder(7), can be forcibly hospitalised and treated under the Act (sections 2 and 3). Admission for treatment can be for up to 6 months, and may be renewed for further 6 months. Afterwards, renewals last one year.

If anorexia nervosa is considered as a mental disorder, it follows that people suffering from anorexia nervosa may be forcibly hospitalised and treated under s. 2 and s. 3 of the Mental Health Act.

Patients who are detained under the Act do not have the right to choose the treatment for their mental condition. Section 63 states that the patients' consent shall not be required for any treatment given to them for the mental disorder from which they are suffering, not being psychosurgery (s. 57) or electro-convulsive therapy and long-term medical treatment (s. 58)(8). However, the Mental Health Act Commission has declared that valid consent should always be sought for the medical treatment proposed, following the guidance given in Chapter 15 of the Code of Practice. This Chapter stresses the importance of giving adequate information to make sure that the patient understands in broad terms the nature, the likely effects and risks of that treatment, and any alternatives to it (para 2.3.1)(9).

The patient's consent is sought because it is understood that the presence of a mental disorder does not necessarily affect the capacity to consent(IO). The law has recognised that incapacity in some ar-

eas of one person's life does not entail incapacity in all areas of her life, "nor does it remove the presumption of competence to refuse [treatment] "(11).

One of the main problems relating to these provisions is what kind of treatment may be regarded as treatment of the mental disorder, as opposed to treatment needed by the person with the mental disorder, and may therefore be lawfully imposed based on s. 63(12). Whether or not coercive treatment may fall within s. 63 is controversial (para 2.4). The Mental Health Act Review Expert Group, appointed in 1999 by the English government to discuss the MHA, has recognised the concern which feeding contrary to the will of the patient has caused in recent years, and has acknowledged the need for clarification on this subject. Moreover, it has recommended that coercive feeding should be included among treatments requiring special safeguards^). The Committee's recommendation has been recently accepted by the Secretary of State for Health(14). '

2§ Eating or Treating? May coercive treatment be lawfully imposed?

The problem of whether or not force-feeding may be imposed under the MHA arose in the Family Division in Re KB (15). This was the case of a 18 years old patient with anorexia nervosa detained under s. 3 of the MHA. Following the court's decision in Airedale NHS Trust v Bland (16), it was stated that naso-gastric feeding is medical (and not psychiatric) treatment, but the problem was whether or not this treatment, namely force-feeding, is given for physical symptoms (e.g. to increase weight), or for the mental disorder. Ewbank J. upheld that "relieving symptoms was just as much as part of treatment as relieving the underlying cause"; therefore, naso-gastric feeding could be imposed based on s. 63(17) (it should be remarked that the case of Bland did not concern a person with a mental disorder, but an individual with no mental function at all).

It should be noticed that the MHA allows the imposition of symptomatic treatment(18), and that, on this basis, in B. v. Croydon District Health Authority (19) it was decided that naso-gastric feeding could be justified based on the MHA, because it can be considered as a "symptomatic" treatment.

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Moreover, in *Re KB* (20) the judge declared that the refused treatment was linked to the mental illness and that, therefore, the patient did not retain capacity to refuse or consent to it. In fact, it has been stressed that a patient suffering from anorexia nervosa may be unable to make an competent choice about treatment for his/her condition(21), as the capacity to give and sustain valid consent may be affected by fears of obesity or denial of the eon-sequences of their actions, notwithstanding the retention of intellectual capacity to understand the nature, purpose and likely effect of treatment (para 2.3.2).

Feeding contrary to the will of the patient was allowed also in *Riverside Health NHS Trust v. Fox* (22). In this case, the judge declared that feeding is treatment within s. 145 of the MHA. Section 145 states that treatment for mental disorder includes nursing, care, habilitation and rehabilitation under medical supervision. According to Sir Stephen Brown, feeding "is an essential part of nursing and care", and "feeding a person suffering from anorexia nervosa is an essential part of that treatment"^).

In fact, in Riverside, the judge upheld that coercive feeding represents legitimate treatment, in the case of anorexia, because any other therapy would be ineffective, unless the patient gains some weight. This position has been supported by Hilde Bruch, a psychiatrist who is famous world-wide for her work on eating disorders, Bruch states that psychothérapie treatment cannot be meaningful if the patient is too severely emaciated, not only because the emaciation may significantly affect the patient's psychological responses, but also because the psychotherapist's anxiety and concern may interfere with the efficacy of the therapy(24). However, this seems to be, in clinical terms, a very much disputed issue. Contrary to Hilde Bruch, Mara Selvini Palazzoli and collaborators argue that the imposition of food may compromise both the efficacy of the therapy and the long-term recovery of the patient, because of the sense of violation that such an imposition may generate in the patient. They maintain that it is likely that the patient tends to lose further weight at the beginning of the therapy and suggest that therapists should not only ignore the fact, but even encourage it, as this would disproof the patient's expectation to receive a response of disapproval. According to the authors, such a disproof would induce the patient to abandon the strategy of thinning(25).

The legal issues relating to coercive treatment for anorexia nervosa evidence one thing: the problem of consent to or refusal of treatment for anorexia nervosa concerns mainly life-saving treatments. As we shall see, for this reason, peculiar bioethical issues surround the case of refusal of treatment for this disorder.

3§ Should patients be allowed to refuse treatment for anorexia nervosa, when they have the capacity to make such a decision?

As we have seen, the English Code of Practice recognises that the presence of a mental disorder does not necessarily affect the capacity to consent to, or to refuse medical treatment(26). Moreover, clinical studies demonstrate that people suffering from anorexia are typically bright young persons, competent in most areas of their life, but trapped by a persistent concern about food and body weight(27).

In the light of these findings, Heather Draper has posed an important question: what should we do if a chronic anorexic patient refuses life saving treatment not because of "irrational views about their body image", as she says, but because she/he is fed up with anorexia and does not feel able to cope any more? Anorexics' quality of life is sometimes very poor. They might decide to refuse medical treatment not being driven from anorexia, but because "the quality of life with anorexia is not good enough to outweigh the burdens of the therapy"(28). Should we respect their decisions, in these cases'?

Draper seems to suggest that, in spite of difficulties involved in assessing the patient's competence to make the decision at stake, it is "wrong not to allow anorexics the right to refuse therapy", when the refusal is based on a competent judgement on the quality of their life.

Apparently, this argument is quite compelling. It is generally agreed that denying people's freedom to conduct autonomously their life, when do not harm others, is to do a moral wrong(30). This general ethical principle has been translated into health-care law, and it is accepted that patients can-

not be submitted to any form of treatment contrary to their will, unless they are found unable to make the decisional). It follows that, at least *prima facie*, anorexics' *competent* decisions to refuse treatment should be respected. Anorexics seem to have a right, at least *prima facie*, to refuse naso-gastric feeding, when they are competently making such a decision. To this right *prima facie*, presumably corresponds a duty *prima facie* of others to respect the patients' wishes.

However, this view is not uncontroversial, because of the peculiar circumstances characterising ending-life in cases of anorexia nervosa.

4§ Informed consent or ending life?

It has seldom been noticed that the problem of compliance to/refusal of treatment of anorexia nervosa is, in some cases, not only a (legal and bioethical) problem of informed consent in psychiatry, but also a (legal and bioethical) ending-life issue.

Unlike other psychiatric conditions, in fact, in anorexia the legal issue of consent relates essentially and directly to life-saving treatments, that is, artificial hydration and nutrition. Consent to psychotherapies is generally explicit, as help is generally voluntarily sought. Will to comply is considered essential to the efficacy of treatment (32), and, therefore, the imposition of psychotherapy is very unusual, and generally confined to the case of psychopathies (33).

All this considered, the many problems (also *terminological* in nature) characterising the debate on ending life cases, arise also in compulsory treatment of anorexia nervosa.

5§ Terminological issues

A number of terminological problems arise when treating ending-life issues(34). However, partly due to the evocative (and often sinister) power attached to some terms (such as euthanasia, for example, or assisted suicide), these terminological problems are not simply a matter of name. In fact, the way we characterise acts and decisions which results in one's death has a crucial importance, both at an ethical and at a legal level. For example, regarding a particular ending-life decision as "suicide" is likely to elicit peculiar ethical and legal dif-

ficulties, linked to the controversial morality and legality of suicidal choices.

It is therefore important to understand how should we characterise the refusal of naso-gastric feeding. There are a number of alternatives:

- 1. Should we regard the refusal of naso-gastric treatment as a case of "refusal of treatment" or as a "suicidal" choice?
- 2. If the refusal of naso-gastric feeding is considered as a suicidal choice, it seems that we should consider the acts and omissions that the eventual respect of this choice requires, as an "assistance to suicide". Instead, if the refusal of naso-gastric feeding is "refusal of treatment", how should we consider acts and omissions that will be required by the respect of this refusal of treatment? Among act and omissions of "suspension of treatment", or of "euthanasia" (maybe voluntary, as it responds to the patient's wishes, and passive, as it requires a non-intervention)?
- 3. If the refusal of naso-gastric feeding is considered as a "refusal of treatment", what is the patient refusing? The intervention on emaciation or on anorexia? This distinction is important, at an ethical level. In fact, it might be argued that capacity to make decisions about thinning is probably undermined by, for example, an erroneous perception of impulses of hunger and satiety(35); or by the questionable perception of body image(36). However, it might be argued that, in spite of the patient's inability to make decisions about emaciation, s/he might be sufficiently aware of his/her condition so as to make decisions about the quality of his/her life. S/he may come to think that living with the continuous and overwhelming fear of fat and weight lowers the quality of life below the limit of tolerability, and may in this sense be able to make a decision on his/her condition. For this reason, it seems to be important to question whether the intervention that the patient is refusing is the intervention on emaciation or the intervention on anorexia nervosa. S/he may be unable to make a choice about the former, whereas able to make a choice about the latter.
- 4. Artificial nutrition sometimes concerns chronic cases: in these cases, may the refusal of treatment be conceptualised in terms of request for suspension of cure? (And, accordingly, may acts

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and omissions, which the respect of this refusal requires, be considered as acts and omission of suspension of cure)? This depends, to some extent, to the plausibility of the conceptualisation of severe chronic anorexia in terms of "terminal" illness. This question is a very puzzling one. On the one hand, in fact, we may have a skeleton-like body at the edge of survival, with serious physical complications and an extremely poor quality of life. On the other hand, however, we are aware of the fact that the secondary symptomatology of anorexia, that is, the effects of starvation, is completely reversible. In front of the complete reversibility of secondary symptomatology, is still possible to conceptualise this condition as a *terminal illness?*

5. Does the fact that the death of the patient, in case of anorexia, is not a "necessary" event (that is, in large part independent of the will and the efforts of those involved), and the fact that secondary symptomatology is completely reversible, affect the normative strength of the principle of autonomy? If, on the one hand, autonomy is of value to all of us (37), and is a principle universally respected, on the other hand, it should also be acknowledged that these are tragically avoidable deaths. Who would not wish to prolong the life of their beloved one in the hope that the "nightmare" finishes as it had started, when knowing that it could finish as it had started, and that everything could "come back to normal"? If it is understandable that people find it sometimes hard and even impossible to accept or tolerate the death of a beloved one, when the death is unavoidable (maybe because it has already occurred), even more we can sympathise with the fact that people may find intolerable the idea of an avoidable death. Do these understandable feelings have any normative strength, at an ethical level? Do they weaken the duty, that we all share, to respect other's competent decisions upon their life?

Conclusions

Sometimes, making choices about our own lives gives rise ethical difficulties. One of the tasks of philosophy, and, perhaps, one of the most important, is pointing out with clarity such difficulties.

Where the case of anorexia nervosa has reached the courts, a number of legal and moral issues have arisen. Due to the rapid spread of the disorder, it is likely that countries where the case of anorexia nervosa is not regulated will shortly have to approach this problem. It seems that part of the legal and moral issues surrounding anorexia nervosa are linked to the fact that refusing treatment for anorexia nervosa sometimes means refusing a life-saving treatment, and, accordingly, that imposing such treatments for anorexia nervosa means obliging someone to continue to live. This fact sets the issue of consent to or refusal of treatment for anorexia at the boundary between informed consent and ending-life decisions. It follows that also a number of problems, terminological, conceptual, and ethical in nature, surrounding ending-life, arise in the case of anorexia nervosa. In this article, some of these issues have been highlighted.

Given the emergency represented by anorexia nervosa, further investigation is necessary and urgent, and readers and experts who I believe to be more skilled than I am will forgive both my attempt to share with them the burden of such an investigation, and the audacity of my hope that I am not abdicating to my job if I conclude my argument with questions, rather than with answers.

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- 6. The Statute is in force also in Wales.

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- For definitions of these terms, see Mental Health Act 1983,
 s. 1(2); see also Brenda Hogget, Mental Health Law, Sweet
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- 9. It should be noticed that the Code of Practice docs not have statutory force, but "it is widely expected (including by the Mental Health Act Commission) that those involved with the management of the Mental Health Act will comply with the Code, and failure to comply might be cited in civil legal proceedings as indicating poor practice or negligence", see the Department of Health and Welsh Office, Code of Practice: Mental Health Act 1983, 3rd ed. London: The Stationery Office, 1999,
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