The refusal of treatment in anorexia nervosa, an ethical conflict with three characters: “the girl, the family and the medical profession”.

Discussion in a French legislative context

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SUMMARY
Anorexic patients are prone to refuse treatment despite life-threatening complications. The therapist's ethical code can be torn between duty to protect life, and law that demands respect of the patient's autonomy. The age of these girls introduces a third participant in this ethical conflict with three characters: “the girl, her family and the physician”. Even if her decision to refuse treatment can appear unreasonable, the patient suffering from anorexia nervosa remains “competent” to receive information concerning her state of health and to make up her own mind about what to do next. French law only recognises for the therapist a real duty to make efforts to convince the patient of the absolute necessity of treatment. However it appears important to confront these legal obligations with different situations created by the disease in order to help pave the way to finding medical solutions capable of conciliating the objective of the best treatment, the own ethical code of the physician and the respect of current legislation.

Key-words: Anorexia nervosa · Ethics.

RÉSUMÉ
Anorexie mentale et refus du traitement
Les patientes souffrant d’anorexie mentale refusent souvent la prise en charge thérapeutique en dépit de complications qui menacent le pronostic vital. L’éthique du thérapeute est partagée entre son devoir de protéger la vie et les exigences de la loi recommandant le respect de l’autonomie de la malade. L’âge de ces patientes introduit un troisième intervenant dans ce conflit éthique triangulaire : « la jeune fille, sa famille et le médecin ». Même si la décision de la patiente de refuser le traitement peut apparaître déraisonnable, celle-ci reste « compétente » pour recevoir l’information concernant son état de santé et pour prendre sa propre décision de la suite à donner. La loi française reconnaît au thérapeute le seul devoir de faire tous ses efforts pour convaincre la patiente de la nécessité absolue du traitement. Cependant il est important de confronter cette obligation légale aux diverses situations créées par la maladie dans le but de trouver à chaque fois la solution capable de concilier la meilleure approche thérapeutique avec l’éthique propre du médecin et avec la législation en vigueur.

Mots-clés : Anorexie mentale · Éthique.
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orexia nervosa is a severe disease occurring during puberty mainly in females. This syndrome, in bringing about great behavioural changes, puts nutritional balance at risk and threatens life itself. It is also a typical example of where there exists a refusal of treatment clearly asserted by the patients. When confronted with this disease, the therapist’s ethical code can be torn between that which his professional conscience is based on, i.e. the duty to protect life, and the law that demands absolute respect of the patient’s autonomy. The age of these girls and their dependence on their parents introduces a third participant into what could be called an ethical conflict with three characters: “the girl, her family and the medical profession”.

Even if her stubborn decision to refuse treatment can appear unreasonable, the anorexic remains “competent” for a very long time to receive information concerning her state of health and to make up her own mind about what to do next. This competency and its limits have recently been evoked by Tan [1]. This author wonders whether the refusal of treatment formulated by the anorexic comes from a decision made by her where she is prepared to accept the consequences, or whether it’s the “voice” of the disease that is speaking through her. For the author, this competency infers the following elements: 1- the subject understands the information; 2- she retains the facts given to her; 3- she applies them to her decision and; 4- she communicates her choice to the carer. It is evident that the anorexic is in a position to receive, understand, integrate the information and to give her decision. She is therefore de facto perfectly competent. The anorexic has a value system where her aspiration to thinness and/or to control dominates all other aspirations. These convictions bring her, depending on the stages of the disease, to deny the possibility of death or accept it or even desire it. In this sense, her attitude is for her perfectly rational. However, the carer can ask himself whether such a turnaround in the patient’s scale of values is not purely and simply distorted by the disease. This type of discussion is found in the report of a lawsuit where, in common law countries, the notion of “competence” had been denied to an anorexic patient and the placing of a naso-gastric tube against her will had been justified a posteriori [2].

French law on the subject only recognises for the therapist a real duty to make efforts to convince the patient of the absolute necessity of treatment, and this by objective means. However it appears important to confront these legal obligations with different situations created by the disease in order to help pave the way to finding medical solutions capable of conciliating that which sometimes appears irreconcilable: the objective of the best possible treatment and the respect of current legislation. But it is worthy to remember that the conflict is not only legal but also ethical. The conflict faced by practitioner is typical of the opposition between two principles of the contemporary medical bioethics [3] i.e. the principle of benevolence and the principle of respecting patient’s autonomy.

Recapitulation of the French legal context: the primacy of the patient’s autonomy, the obstacles to consent, exceptional situations [4-6]

The primacy of the patient’s autonomy [4,5]

The law of 4 March 2002 relating to patients’ rights and to the quality of the health system is unambiguous here because it, in article L. 1111-4 of the French public health code, states:

“With the health professional and taking into account the information and facts that are supplied by him, each individual takes the decisions that concern his health.”

“The physician has to respect the individual’s will after having informed him of the consequences of his choices. If the individual’s wish to refuse or interrupt a treatment puts his life in danger, the physician must do everything possible to convince him to accept the necessary treatment.”

“No medical act or treatment can be practised without the free and informed consent of the individual and this consent can be withdrawn at any time.”

In all of these prescriptions it can be seen that the patient’s autonomy is respected absolutely. The physician’s role is to inform the patient of the benefits and risks to his health and quality of life of the two options that are the acception or refusal of the proposed treatment. The physician is obliged to give to the patient clear, honest, and appropriate information about his illness and treatment that is adapted as the patient’s situation changes (art 35 of the French code of medical ethics of 1995). This information must be objective, in language that the patient can understand, without excessive dramatisation, and it must be complete. The patient’s decision must be given freely, without pressure.

These rules are necessary for physicians, even though the professional rules that govern medical practice are not in keeping with this: 1- the imperative duty to care and treat (art 9 of the French code of medical ethics – art 223-6 of the French penal code) and 2- the obligation to personally ensure for the patient care that is based on acquired scientific facts (art 32 of the French code of medical ethics) [6].

Obstacles to consent, exceptional situations

There are a few exceptions to this fundamental liberty that is the patient’s autonomy. They are mainly to do with obstacles to consent. For the anorexia nervosa that we are interested in here, these possible exceptions are due to a status of “legally incompetent” (minors, adult wards of court), a state of unconsciousness or lastly to particular and highly
defined situations linked to mental disorders (Law of 27 June 1990).

The law of 4 March 2002 states that “The consent of the minor or the adult under guardianship must systematically be sought if he is able to express his wishes and participate in the decision.” as is also stated in article 42 of the French code of medical ethics. For unconscious persons, that is to say it is provisionally impossible for them to consent, the law of 4 March 2002 envisages delegation of consent to a person of trust. Finally, the French legislation foresees two types of hospitalisation against the patient’s will when his capacity to consent is called into question and under certain conditions.

The first type is hospitalisation “at the request of a third party”. Two cumulative conditions are foreseen for this hospitalisation decided by a member of the family or an individual likely to act in the interest of the person (art L.3212-1 of the French public health code):
– That the mental disorder that the person is suffering from makes his consent impossible.
– That his condition necessitates immediate treatment along with constant monitoring in a hospital environment, notably when the individual’s behaviour compromises his security and that of those around him.

The second mode of hospitalisation against the person’s will concerns the intervention of the administrative authorities in the case of individuals “whose mental disorders necessitate treatment and compromise peoples’ safety or seriously breach the peace” (Art L. 3213, French public health code).

Application of these principles in the various situations of refusal of treatment during the course of anorexia nervosa

In fact, the physician can be confronted with the refusal of treatment in three situations that are of varying severity but that all question their professional ethics i.e. denial of necessity of medical treatment, refusal of hospitalisation when the vital prognosis is at stake, or the demand of euthanasia.

The refusal of initial treatment

It is at this stage, when the illness is developing in the girl in a “flamboyant” manner, that the discourses of the three members are the most divergent.

The medical profession’s point of view [7,8]

For the physician, it is an illness that is perfectly characterised according to consensual clinical criteria (DSM-IV), that is very serious for the vital and functional prognoses not only in terms of mortality in the long-term but also in terms of associated pathologies, in loss of fertility and social and familial maladjustment [8]. Finally, he knows that early and good quality treatment can favour a better outcome [8]. But he is also aware that medical treatment for the illness is impossible unless the girl accepts and actively participates in it. Medical care is but an accompaniment, coaching. The anti-anorexia nervosa pharmacopoeia remains to be discovered. Psychotherapy cannot be prescribed, it is offered and it is impossible without the desire or, at best, the commitment of the patient. He cannot guarantee recovery because he knows that even in the best centres, the level of recovery does not exceed 55-60% [8], and that the treatment technique is empirical because a method of reference does not exist in this domain [9]. There exists legitimate doubt on the effectiveness of treatment.

The family’s point of view [7]

The family often behaves ambiguously since it has not got the full measure of the illness from which their child is suffering. The parents feel a certain anxiety when faced with the physical and behavioural transformations in their girl (realisation that is often however belated). They are aware that the intra-familial dynamic is completely disturbed by the illness. They are exhausted, feel guilty, and are unable to exercise their parental responsibilities.

However there exist conscious and subconscious limits and constraints to their action. They respect what their child says, even when on the brink of delirium. They feel weak vis-à-vis the repeated manipulations or promises not kept by their child. They fear of delegating their responsibilities as parents, without control, to a third party (which would result in reinforcing their idea that they are bad parents and aggravating their feeling of guilt).

This ambivalence has them demanding medical treatment all the while wishing to be reassured of the mildness of the illness involved.

The girl’s point of view [7]

She, on the contrary, is certain of her good health and judges any insinuation of considering her as ill as being an aggression. Her situation is characterised by the absolute denial of the illness and the refusal to recognize the least seriousness or an eventual risk associated with her condition. She supplies proofs of her perfect state of “health”; success at school, hyperactivity, extreme willingness to help within the family. She is unable of seeing how thin she is, except sometimes from fleeting images that are quickly forgotten. She draws advantages evident from the current state of affairs: slimness finally obtained (personal success, envied by many), a body image close to her most profound aspirations. Facilitation of the hyperactivity by the weight loss confers to her an impression of omnipotence.

If the other members of the ethical trio have doubts, she hardly has any doubts regarding her anorexic behaviour. The displeasure of being hungry, the daily exhaustion or the first consequences of slimming are transformed into pleasure. Also the girl appears unmoved; denying the illness and refusing absolutely that one could oppose her
desire to lose weight. Medical reasoning has scarcely more influence on her determination than the entreaties or the injunctions of her relatives. She subscribes to an illusion of immortality that enables her to believe that she can approach the limits of life without risk.

How can this triangular situation, which is perceived in different ways by the persons concerned, be managed?

The aim is to obtain the conviction that we are dealing with a genuine illness with particularly serious short- and long-term consequences and the consent to treatment. In fact, in this case, the word consent is too weak because it is about obtaining personal commitment to fight the illness.

The strength of conviction obligatorily involves a mark of authority but this, in having the aim of extracting consent without violence, must respect the patient’s free will. This mark of authority can be medical (“medical expertise”), parental (“parental responsibility”) or indeed come from one’s circle of friends (“friendly concern”).

Medical expertise

At this stage, it is about convincing and not obligating using information that is “honest, clear and appropriate”. The affirmation of the “anorexia nervosa” diagnosis and of the severity of its prognosis must be done in plain language, without beating around the bush. Its psychiatric nature must be asserted. The vital prognosis that is at risk and the long-term consequences in the absence of recovery must be detailed. In developed forms one can use nutritional assessment data of which some biological anomalies are sometimes already there to prove the beginning of undernourishment. The main treatment features and their consequences must be described. This phase, if the adult girl is in agreement, must be public in the presence of the family that could itself be simultaneously convinced and serve as witness of what is said.

The responsibility of parental support

This parental authority that persists in spite of everything should always be used, at least partially. It is necessary that the carers and the parents form an alliance to together put pressure on the girl’s determination in order to bring her to consent. It is, in general, easier when the girl is a minor, but the role of the parents is often important even in anorexic patients who are of adult age.

Friendly concern

The alliance can sometimes be reinforced by a third party who could be another member of the family or even a close friend, who plays a role of moral or emotional authority. It could also be the family doctor or another specialist, or a relation admired by the family.

If these acts of power, of which the sole aim is to convince the patient, are ineffective at weakening the girl’s stubborn determination to recognise the illness, what option to choose between coercion that is difficult to do at this stage and is in fact forbidden by law or the direct or indirect relinquishing of responsibility? There exists an intermediary solution. A possibility of contact in the expectation of progression towards a phase of suffering from the illness could be maintained.

It is worthy to note that the Conseil National de l’Ordre in its report of 29-30 January 2004 [6] states that prudence requires that a practitioner confronted with an absolute refusal of treatment does what is necessary to be able to justify a posteriori that his information was appropriate [6].

At the undernourishment stage risking the vital prognosis in the short- or medium-term

Undernourishment, the consequence of severe and prolonged nutritional restriction is a serious complication of anorexia nervosa. It is one of the causes of excess mortality noted in girls [8,9]. It necessitates medical treatment comprising, if the refusal to eat persists, of refeeding by nasogastric treatment and/or drip. Persistence in the refusal of treatment at this stage is life threatening for the girl.

The physician

The existence of severe undernourishment with well-codified clinical or biological stigmata questions the professional conscience of the practitioner. With the vital prognosis affected, the practitioner could be tempted to adopt a paternalistic attitude by disregarding the patient’s autonomy. She would be in a state where she would be incapable of taking into account the risk to her life, which has a certain element of truth. Confronted with medical information, she would choose an unreasonable solution. The illness would render her partially incompetent. It must be noted that an unreasonable (in the mind of the physician) opinion does not automatically signify incompetence, because it could have its own logic for the patient [1]. He also knows that the release from undernourishment by resuscitation and refeeding has considerable chances of modifying the patient’s behaviour and that temporarily at least she could find herself feeling more inclined to envisage her participation in treating her illness.

The family

At this stage the parents have become fully aware of the seriousness of the situation and demand urgent treatment for their child. They are in a panic and cannot understand the ethical limitations that appear to justify to their child’s apparent desire to die. They revolt against the medical profession’s attitude that seems to them to verge on failure to render assistance to a person in danger.

The girl

She can persist at this stage in her refusal of treatment. She no longer denies the illness that has become too evi-
dent, but she refuses to see or believe in the imminence of death. Above all, she has such a fear of having to relinquish her rules of control, so severely installed and that sum up her value system, that she is prepared to sacrifice to them all her other aspirations and life itself, if need be. Undernourishment also involves a certain inertness of thought. She is absolutely incapable of extracting herself from this dilemma formed of the will to maintain the state of control and this extreme despondency. She subconsciously hopes that a third party will be able to make the right decision and she is incapable (or that she forbids herself) to make herself [10].

**How can this emergency situation be handled?**

French law hinders any attempt at paternalism and coercive treatment, even at this stage. The law of the 4 March 2002 makes the patient’s consent the foundation of the treatment. The same applies to psychiatric patients. If refusal of treatment puts the patient’s life in danger, the physician in accordance with the law of 4 March 2002 “must do everything possible to convince the patient to accept the necessary treatment” and must inform the patient of the “foreseeable consequences of the refusal”. There again, the physician has recourse only to the power of conviction. However, he must not yield too easily in front of the refusal that he is given. He could be blamed for this relinquishment (ruling of the French court of appeal, 7 November 1961, cited in 5). It is truly required of him to “do everything possible” to obtain the patient’s consent. It must be said that the physician is left alone to face an inextricable situation, is in a veritable impasse where equally respectable obligations that are respect of the individual’s freedom, compassion towards the anxiety of the families and his own professional ethic to fight suffering and death are in opposition to each other.

Hospitalisation at the request of a third party is envisaged by certain parents of anorexics, thrown into a turmoil by their child’s critical situation, but this solution must be considered particularly dangerous. There are several obstacles to this. It is difficult to maintain that even the highly undernourished but conscious girl is incapable of consenting. Moreover, her psychiatric hospitalisation, obligatory for this type of placement, is not adapted to her condition that requires specialised medical treatment and monitoring. Finally, despite her placement, her refusal to eat, if it persists, can only be respected. It would be risking more to persist especially if hospitalisation had been obtained against the patient’s wishes. This solution appears to be more a means of reassuring the parents than a truly effective path towards the patient’s commitment to treatment.

An interim ruling of the Conseil d’Etat of the 16 August 2002 opens the door to a possible adjustment of a strict application of the law of 4 March 2002, when the individual’s life is at stake. In this affair that concerns the possibility of liberating hospital physicians from the strict refusal by a Jehovah’s witness patient to be given a transfusion if it became necessary, the interim high authority judge justifies his opinion with the following considerations:

“Considering that the right of the adult patient to give, when he is in a state to express it, his consent to medical treatment is a characteristic of fundamental freedom; considering that the physicians do not, however, seriously, and clearly illegally, undermine this fundamental liberty, such as is protected by the provisions of article 16-3 of the French civil code and by the provision of article 1111-4 of the French public health code, when after having done everything to convince a patient to accept the necessary treatment, they accomplish, in the aim of trying to save him, an act indispensable to his survival and proportional to his condition; considering that in such conditions recourse to an act of this nature is not, either, manifestly incompatible with the requirements of the European Convention for the Protection of Human Rights and Fundamental Freedoms, and notably of its article 9.”

This judgement is only an indication of a possible development but it cannot formally be retained as a precedent because it was an interim ruling given by a single judge. It does however show the ambiguity of the law of 4 March 2002 that implicitly points to the possibility of passive euthanasia when the latter however remains forbidden by French law.

**The renunciation or the desire of euthanasia**

In a certain number of cases, the patient has accepted the principle of treatment, she submits to the apparent constraints of this but by covert efforts, she takes all sense away from this treatment. She gets into a state of dependence vis-à-vis the carers, all the while demonstrating the vacuity of their action. Thus she gets into a state of wasting away to the point of undernourishment. Life is no longer even in danger, only drained of all desire or élan. In other words, she includes the treatment itself in its syndrome. On the contrary, here, there is a demand for medical treatment and it is the carer that wants to break this link that confirms her incapacity to get better. The family, often exhausted at this stage, is no help, they themselves have given up as well. Thus great patience is required of the carers.

Arrived at the end of a long succession of treatment riddled with numerous relapses, the girl can consider that she is at an irreversible stage of a debilitating, invalidating disease that generates unbearable mental and physical pain. Moreover, suicides are quite frequent at this stage. She can consider the proposition of treatment that is made to her as a prolongation of life by medical means and categorically refuse it. Her request finally comes down to a passive demand for euthanasia even if certain authors think that this situation remains in the context of a simple respect of competent refusal of treatment (cf. the exchange of viewpoints between Draper and Giordano, [11-13]. Sometimes
even, certain doctors go with this wish of the patient, by organising real palliative care [14]. These, thankfully, highly exceptional cases are the subject of real debate in medical literature, debate dominated by a feeling of reproba-

tion [15,16]. The reason for this disapproval is that incur-

ability is never certain, even at this stage of chronicity. All practitioners interested in this pathology have seen improvements and even recoveries after long years of setbacks or relapses. Furthermore, anorexia nervosa cannot be seen as a debilitating disease that progresses inexorably, such as terminal cancer for example, when we know that refeeding makes it possible for at least a partial reduction in the clinical consequences of the illness and eventually offer new chances for the future [15,16]. Moreover, this active attitude does not exclude the usefulness of reducing patients’ suffering at this stage of the illness, by using opi-

ates if necessary [17].

In conclusion, the French physician’s room to manoeu-

vre when faced with the anorexic patient’s refusal of treat-

ment is limited. He has to walk a tightrope between the non-respect of the individual’s autonomy and the relin-

quishing of his role as therapist. Power of conviction is
demanded of him, which would enable bringing the girl not only to consent but also to commit to the therapeutic process.

Finally, the appropriate attitude when faced with this disconcerting, provocative, sometimes revolting and often discouraging illness could be modest tenacity. Modesty due to our ignorance of the mechanisms of the illness, our incertitude regarding the real efficacy of our treatment action, a success rate that is disappointing and above all our incapacity to predict its outcome in a given patient. It is also to be considered that the patient is of a logic different than that deduced by our medical knowledge. The respect of what appears to us as irrational demands tolerance for the individual though without leniency for the illness and for its desire for death. These points have been recently recalled in general recommendations of French Ethics Committee, CCNE, [18]. Tenacity is also justified not only by the fre-

quent chronicity, but above all because whilerver life remains, whilerver the fight against the illness persists, it is impossible to exclude the possibility of a favourable out-

come, even after long years riddled with repeated relapses. We recall J. Russel’s phrase exhorting the doctors who take care of these patients to never give up and to “fight for every mouthful!” [19].

Acknowledgements – We are indebted to Ms M. Vialettes, Counsel of the Conseil d’Etat and to Pr. G. Bouvenot Chairman of the CCPPRB Marseilles-2 for their enlightened opinions.

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