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S Moratti

ABSTRACT

Over the past 50 years, technical advances have taken place in medicine that have greatly increased the possibilities of life-prolonging intervention. The increased possibilities of intervening have brought along new ethical questions. Not everything that is technically possible is appropriate in a specific case: not everything that could be done should be done. In the 1980s, a new term was coined to indicate a class of inappropriate interventions: “medically futile treatment”. A debate followed, with contributions from the USA and several western European countries. A similar debate later took place in Mediterranean countries, although with a different terminology. The purpose of this article is to provide an up-to-date and systematic analysis of the concept of futility, and to draw some conclusions on its operationalisation in medical practice. While the concept of “medical futility” in theory applies to all kinds of medical intervention that might be performed without being medically indicated—things such as certain medical screenings and cosmetic surgery—in practice the literature on “futility” deals only with life-saving and life-sustaining medical interventions. This article deals with this more limited application of the concept of “futility”.

HISTORY AND FUNCTION OF THE NOTION OF “FUTILITY”

Rather than a comprehensive review of the literature, this part of the article is an interpretation of key passages in the development of the “futility” debate and will serve the purpose of grounding the second part, in which a more substantive contribution to the debate is provided.

The origins of the notion of “futility”

The notion of “medical futility” first appeared in the 1980s. Its function was that of putting a limit to the increasing requests for treatment that patients felt entitled to make to doctors. After the 1960s and the 1970s, the principle of patient’s autonomy was interpreted in a more and more radical way. Besides feeling that they had the right to refuse an unwanted medical intervention, with increasing frequency, patients (or their family or representatives) were demanding specific treatments that doctors had not offered.

Part of the medical world would object to this very ample interpretation of the principle of patient’s autonomy. Legally and ethically, the position of the patient who refuses a medical intervention is radically different from that of the patient who demands one. It is not difficult to find a foundation for the right to refuse medical treatment in the criminal law provisions prohibiting unwanted invasions of bodily integrity. It is quite a different matter to find legal and ethical grounds for providing patients with the power to oblige a doctor to perform an intervention that the doctor considers inappropriate and contrary to his or her professional standards.

The core issue in the “futility” debate is the role (and the authority) of the doctor in the decision-making process over abstention. The notion of medical futility was first introduced as an ethical and legal justification for unilateral abstention decisions made by doctors. If treatment is “medically futile”, a doctor has the power to withhold it (or withdraw it) even over the objections of a competent patient (or proxy). In 1983, a provocative contribution opened the futility debate, by designing a policy giving doctors the power to make unilateral do-not-resuscitate decisions for patients in long-term care institutions. The argument used there was that, in some cases, “clinical indications should be given priority over patient autonomy”. The power of the doctors was based on their medical technical expertise.

Ever since its first appearance, the notion of futility has been the object of strong criticism. Some saw in it an attempt to reintroduce medical paternalism (ie, the longstanding assumption that “the doctor always knows best”). Assessing futility in an individual case is not a hard and technical medical judgement, critics argued. Rather, it is a delicate decision based at least in part on highly subjective, soft and normative evaluations of quality of life. Doctors should not be given the power to impose on their patients their own personal values “under the guise of medical expertise.”

From “futility” to “physiological futility”

In reaction to the criticism, proponents narrowed the scope of the notion of futility. They maintained that the primacy of technical medical expertise (and, in connection with that, the possibility to exclude the patient from the decision-making process) applies only to cases of “physiological” futility—that is, when the treatment will not achieve the biological result intended, and assessing its futility is therefore an objective and technical operation not involving any normative quality-of-life judgements. But attempts to determine more specifically the content of the notion of “physiological” futility did not have...
more convincing results than the earlier attempts to define futility in general.

Some contributions suggested that prognostic scoring systems are the right instruments to shed light on the notion of "physiological" futility. Prognostic scoring systems or mortality probability models consist of statistical information concerning the risk of hospital (or intensive care unit) mortality for critically ill hospitalised patients. Scoring systems are mostly used in the context of intensive care, and can be classified as: general; disease-oriented (eg, severe burns); and patient-group oriented (eg, children).

It is universally acknowledged in the medical world that scoring systems are a good instrument to substantiate clinical judgements of futility through empirical data. However, they cannot explain individual deviations from the predicted outcome. Knowledge that the patient belongs to a group with 80% mortality, rather than a group with 5% mortality, is certainly relevant for decision making, but does not lead to a definite prognosis with regard to the individual patient. In order to make a decision over treatment (or abstention) in the individual case, data provided by scoring systems must be integrated with evaluations of a less hard and technical nature.

In conclusion, the notion of "physiological" futility has been subjected to the same criticism as that of futility in general. Unless life-prolonging treatment is impossible (eg, surgical treatment for certain pervasive brain cancers), the choice whether to intervene is always made (to a narrower or broader extent) with "normative" considerations of quality of life in mind. The notion of futility can best be represented by an unbroken line, ranging from situations in which technical difficulties related to the intervention are of such magnitude that quality-of-life considerations have only a minor role (eg, continuing blood transfusion when pressure cannot be stabilised) to situations in which treatment would in theory be indicated but would lead to a poor quality of life. Decisions in some cases are certainly more value laden than in others. However, the difference between the two is a matter of degree and the grey area between the two is far larger than the extremities.

By the early 1990s, it was generally understood that a purely technical assessment of futility was not possible. There was increasing scepticism about the idea of doctors' power to make unilateral abstention decisions on the basis of their clinical technical expertise. Proponents tried to maintain the original function of the notion of futility by seeking a definition of "futile treatment" that could be the object of ample professional and social consensus. It was assumed that the presence of such consensus would provide a justification for unilateral abstention decisions. In this respect, mention must be made of the contribution by Schneiderman and colleagues.

The contribution by Schneiderman and colleagues
Schneiderman's contribution is often believed to have represented a turning point in the futility debate. Their work aimed to find a definition of futility that the majority of society (including the medical world) would find acceptable, which could serve as a basis for doctors' authority to make unilateral abstention decisions. The debate in the 1990s was a series of reactions to Schneiderman et al.

Schneiderman et al held that the futility of a treatment can be measured according to a quantitative and a qualitative parameter. According to Schneiderman et al, an intervention can be defined as "quantitatively futile" if doctors conclude "through personal experience, experiences shared with colleagues or consideration of reported empiric data" that in the last 100 cases a certain intervention was "useless".

The concept of quantitative futility does not constitute a significant innovation in the debate, as it is merely a way of interpreting statistical data collected in prognostic scoring systems and medical literature. More precisely, it is a quantification of the minimum percentage of intervention failures, below which the predictive power of statistical data can be considered strong enough to justify an abstention decision. By "useless intervention", Schneiderman et al mean "treatment that fails to benefit the person, even if it contributes to the functioning of the organism." A "qualitatively futile" intervention is instead "any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care". This is an attempt to define a minimum standard of quality of life, below which life-prolonging treatment is futile.

The definition of futility by Schneiderman and colleagues of futility was criticised. Schneiderman, and Jecker and Jonsen, addressed some of the criticisms. However, they did not respond adequately to some of the most compelling arguments, which I will summarise here. Some critics pointed out that the 1% percentage requirement of quantitative futility for legitimating abstention is so low that it makes the notion of futility essentially useless. Others maintained that, contrarily to what Schneiderman and colleagues claim, the notion of quantitative futility does involve value judgements as it presupposes a certain definition of what a "personi" is. Still others attacked the idea of qualitative futility because it does not provide indications for the truly ethically challenging situations. It refers only to "constant monitoring, ventilatory support, intensive care nursing, conditions associated with overwhelmingly suffering for a predictably brief time, to the extent that [the patient] cannot achieve any other life goals" and excludes patients whose conditions require "frequent hospitalisation", patients in "nursing homes" or patients who have "severe handicaps".

It seems realistic to think that the reason Schneiderman and colleagues have kept the definition of futility so restrictive is that there is no sufficient professional and social consensus on a broader definition of futility. The idea behind their contribution was certainly original and brave. They tried to find a consensus, a common ground, on what was in fact a very controversial issue. However, the criticism that their work has received, and their own cautiousness when it came to actually specifying the content of the notion of futility, have shown that their attempt was perhaps too ambitious.

The shift to a "procedural" approach
Since the mid-1990s, attempts to define a "medically futile treatment" were gradually abandoned. Once it was established that no consensus could be reached on a definition of futile treatment broader than Schneiderman and colleagues, there was a major switch in the approach to the operationalisation of the notion of medical futility. Attempts were made to engineer procedures regulating the powers of the various actors involved in the decision-making process, aimed at minimising (and, where possible, preventing) conflicts. The original function of the notion of futility was maintained by giving the last word to doctors in case of irresolvable disagreements with the patient (or representative). The country with the most experience with institutional futility guidelines is the USA. This might be connected with the influence of the 1999 report by the Council for Ethical and Judicial Affairs of the American Medical
Association, establishing a model procedure which had a major impact on the futility debate. Several decision-making procedures were elaborated in the line of the AMA model and adopted at the institutional level or at a broader level.

WHY A “PROCEDURAL” APPROACH TO MEDICAL FUTILITY: ROLE OF THE MEDICAL PROFESSION

The notion of medical futility has been approached from different perspectives. I will give a brief account for each, and argue that only the latter is consistent with a procedural approach to medical futility.

Futile treatments interfere with the “natural” process of dying

Proponents of this idea maintain that there is a natural lifespan that human beings are meant to live. Artificial shortening or prolongation of the natural lifespan is morally wrong. This approach was originally developed by the Roman Catholic Church and has been adopted by various philosophers for the intuitive appeal it seems to have, as long as it is exclusively applied to much older individuals. The wise man who has children and grandchildren, and has had all of the most important life experiences, accepts death as the natural, inevitable conclusion of life. Some have gone so far as to making this attitude towards the end of one’s life morally imperative, arguing that there is “an obligation to accept death.”

However, lethal illnesses also affect the young. Paradoxically, a baby who is born with a condition incompatible with long-term survival can be regarded as a terminally ill patient from the moment of his birth, although life has hardly offered him anything yet. Nature destined some to die much younger than others, and it does so regardless to the amount of fulfilling experiences that the person has had. Nature does not seem to always arrange events in a fashion that conforms to our intuitive sense of justice.

Not all human beings are given equal possibilities. The fact that this is unavoidable does not entail that it is fair. It seems therefore that we should not derive our criteria of justice from biological processes that in themselves do not have any moral connotation. For this reason, this perspective on medical futility based on the idea of nature should not be adopted.

“Futile” treatments constitute a waste of resources

According to the proponents of this idea, the futility debate is ultimately a controversies about the allocation of scarce and expensive healthcare resources. Futility is a criterion of distributive justice for the rationing of healthcare, where the organisation of the healthcare market makes cost-containment necessary.

In democratic countries, the healthcare market is divided into two segments. Part of medical care is directly sold to individuals who pay for it out of pocket, whereas the rest is provided by public or private insurers that spread the costs of the interventions. Proponents of the economic approach to medical futility believe that considerations of futility are primarily relevant for the latter segment, where scarcity of resources makes it necessary to elaborate criteria for triage (that is, for limiting expensive interventions to situations where they are most cost-effective). The term triage originated in military medicine, and refers there to the classification of war casualties into different categories, so that the scarce care available can be concentrated on those patients who are likely to survive if treated. The use of the concept was extended to civilian medical practice in the 1960s in connection with the distribution of newly introduced and expensive lifesaving interventions such as dialysis and organ transplantation.

Introducing criteria for access to healthcare based on considerations of distributive justice can be a responsible choice in contexts of severe shortage of resources connected with war emergency or poverty. However, such criteria create unjustified inequalities if extended to situations of peace, democracy, and economic prosperity, when it becomes possible to engineer social policies that prevent scarcity of healthcare. It should be possible for doctors to work in a context that does not force them to discriminate against some patients. Society should provide the medical profession with such a context, through adequate policies. Promoting equity in the healthcare sector is a fundamental political virtue for a society, rather than one of the ethical cornerstones of medicine. Medical ethics (among them futility) pertains exclusively to the appropriateness of treatment for the individual patient, judged in the sole interest of the patient and in the light of the patient’s well-being and expectations for the future. Expensive interventions should not be labelled futile to justify denying them to certain human beings on grounds of lack of resources, nor should non-expensive and non-scarce treatments (for example, artificial nutrition and hydration) be initiated (or maintained) if doing so is not in the interest of the individual patient. In conclusion, the medical futility debate should not involve considerations pertaining to rationing of healthcare resources. “Futility” and “rationing” are distinct concepts, and, unlike some have claimed do not overlap, not even partially.

Administration of a “futile” treatment is a violation of medical professional standards

The third perspective on medical futility is based on an analysis of the scope of the professional autonomy of doctors. I shall argue that this idea, unlike the preceding two, is analytically sound and is fully consistent with a procedural approach to medical futility.

The legal basis of this approach to futility concerns the relationship between the legal system and the authority to practise medicine. Both civil and criminal laws prohibit intentional or negligent violations of physical integrity, unless justified or excused by another legal provision. However, a large part of the professional behaviour of doctors consists precisely of invading the body of the patient, and hence the need of a legal instrument to exclude the liability of doctors who act in their professional capacity. This instrument is the “medical exception”, a non-statutory (or implicit) exclusion of medical behaviour from the coverage of those provisions of the criminal law that protect the integrity of the body. It differs from a justification in that the medical exception does not itself prescribe how the behaviour that otherwise would violate the civil and criminal law is to be carried out. In effect, this is left largely to self-regulation by the medical profession. Thus, the medical profession enjoys a certain degree of autonomy with respect to the legal system.

The authority to practise medicine is not without limits, and the medical exception applies only if the behaviour of the doctor remains within them. First, the behaviour in question must not be specifically prohibited by the law. Many medical procedures are clinically possible but illegal in most countries. Abortion beyond the twenty-fourth week of pregnancy is an example. Second, the patient, if competent, must have consented to the medical procedure and the consent must be voluntary and well informed. If the patient is not competent, most legal systems allow a surrogate to act as a substitute consent-giver.
The consent requirement has exceptions. Obtaining consent may not be possible in emergencies where the patient is unconscious and treatment decisions have to be made quickly. The unconscious patient taken to hospital after a traffic accident receives life-saving treatment if immediately necessary, available and appropriate, regardless of being unable to consent. Albeit non-consensual, the medical intervention here does not violate civil or criminal law because it is performed in a situation of necessity, in order to prevent an immediate danger to life. This situation is becoming increasingly frequent in the intensive care setting, where doctors need to make decisions quickly and to win time in order to make a diagnosis that will serve as a basis for further treatment decisions.

Finally, doctors must intervene in accordance with professional standards. The expression “professional standards” encompasses two sets of rules. First, doctors must act with the technical medical skills that form the core of the profession, and exhibit due care in performing their professional duty. Incompetently making a wrong diagnosis or negligently forgetting a surgical tool in the patient’s womb are violations of professional standards. Second, professional standards include criteria of appropriateness in giving medical care laid down in official clinical guidelines. Such guidelines are based on a combination of scientific evidence (eg, clinical studies or practice guidelines) and medical ethical considerations concerning patient welfare. Medical futility is an example of such a professional standard. Performing a futile treatment does not amount to incompetence or negligence in the strictest sense, but it does constitute a violation of a medical professional standard, and the medical exception therefore does not cover it.

In conclusion, futility can be considered as a negative standard limiting the authority to practise medicine. It is not within the authority of the members of the medical profession to invade the patient’s physical integrity by performing a futile intervention, nor is it within the powers of the patient (or representatives, or other actors in the decision-making process over futility in individual cases, including courts) to oblige a doctor to do so. This holds, in particular, for medical procedures that amount to a violation of the principle of beneficence, involving the infliction of iatrogenic harm without the prospect of markedly improving the patient’s condition.

CONCLUSIONS

Beyond their conceptual differences, the various attempts to operationalise futility all aimed to maintain the original function of the notion, that is, giving doctors the possibility to make abstention decisions against the will of the patient or representative. The notion of futility represented an attempt by the medical profession to defend its role, increasingly undermined by requests from patients (or representatives) who would confuse the right to refuse an intervention with the right to demand one.

It is nowadays established that “futility” can best be operationalised through a procedure regulating the allocation of decision-making powers among the various actors involved in the decision-making process. More specifically, in line with the American Medical Association model, the procedure should aim to promote communication, minimise conflicts between the various actors (potentially) involved and avoid (where possible) polarisation of conflict and mobilisation of formal legal institutions. In case of irresolvable disagreement between doctor (or medical team) and patient (or representative), it should be possible to transfer the patient to a different doctor, medical team or institution willing to provide the intervention. However, not every treatment that could theoretically be administered should be administered. The intervention should not be performed if there is general consensus in the medical community that it would be futile in the patient’s case. General consensus here entails that (1) the doctor(s) who are already treating the patient have come to the conclusion that the treatment is futile in the patient’s case, and (2) their conclusion is supported by second opinions from independent doctors and medical centres and is based on professional guidelines and clinical studies. Intervening would amount to an invasion of the patient’s physical integrity nor justified by “medical exception”.

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