# National Consultative Ethics Committee for Health and Life Sciences

# Opinion nº 81

Performance and health

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On April 30<sup>th</sup>, 1999, Bernard Kouchner, Minister for Health, referred to CCNE for an opinion on "ethical issues raised by the propagation of new medical techniques which do not fit into the scope of the 1988 law on the protection of persons accepting biomedical research". This raised the issue of the ethical value of the "cult of performance" which is in many ways characteristic of society and culture in the world of today. CCNE therefore felt it necessary to broaden the scope of the referral to other aspects of the relationship between the quest for performance on the one hand, and health on the other, instead of restricting their study to the sole domain of medical performance.

Clearly, performance is sought after in other areas, such as economic productivity, art, literature, but these are far from being within the competency of CCNE, which quite obviously, has no mandate to be a moral authority issuing peremptory pronouncements about society as a whole.

Performance seeking does characterise to a great degree contemporary society, and there is an abundance of publications on the market to evidence the fact². This quest has important consequences on health. The undeniable progress that has marked the advancement of the biomedical sciences in the last few decades, the important improvements to health that they have brought about, could be damaging if the quest for exploits or performance at any cost becomes the primary consideration. In the medical field itself, spectacular operations mobilise considerable resources – to the detriment frequently of other therapies – with disputable results; precarious therapies raise unconsidered hopes; so called "leading-edge" techniques can never be useful to more than a limited population. In sports, the cult of performance generates a ceaseless effort to go higher, faster, and further. Doping is the cause of grave health risks when the body is prematurely exhausted because its essential demands have been ignored.

To speak of medical and sports performances in the same Opinion, and to liken medical or surgical intervention to doping, may seem a little illogical at first sight. Surely, medical performance only seeks to be beneficial. Sports performances clearly provide enjoyment for spectators ever more fascinated by an escalation of exploits to be beaten. World records are fleeting in essence and there to be broken.

But these two disciplines (and these are disciplines) play for the same stakes when the question of performance arises.

- possible instrumentalisation of human beings for purposes beyond their control.
- disregard for the respect of human autonomy which may become more virtual than real.

Ever increasing biological pregnance gives rise to socio-biological pregnance which highlights biological inequalities. Constant compensation for them, in the form of medication, prosthetics, or doping, must be provided. As a result, the cultural context encourages biological intervention in sports competitions, and unlimited prostheses in scientific competition. Relentlessly, new techniques, new markers, new substances have to be invented to push back the boundaries.

### I. Modern society and performance<sup>3</sup>

## 1. Approved performance

<sup>1</sup> This concerned, inter alia, the spectacular graft of a forearm harvested from a cerebral dead donor at the Hospices Civils de Lyon, and the development of in vitro fertilisation techniques, in particular intracytoplasmic sperm injection, and of more immature forms of spermatozoa.

<sup>&</sup>lt;sup>2</sup> Simply consulting one bookshop site on Internet provides the titles of more than 150 books available in French on the subject of performance and how to improve it.

<sup>&</sup>lt;sup>3</sup> Cf. in particular Alain Ehrenberg, *Le culte de la performance*, Hachette Littérature, Pluriel, 1999 ; D. Le Breton, *Conduites à risque*, Paris, PUF, 2002.

The quest for performance cannot of course be rejected wholesale and indiscriminately. To return to etymology, *per-formare*, means to give form, to make real, to abandon the more or less superficial domain of dreams in order to give substantial life to ideas or projects. To that extent, performance – the use of particular capacities – is certainly within the true essence of *homo faber*. It in this regard for instance, that hospital performance is a manifestation of the quest for better routine quality indicators.

The use of the word linguistically is further evidence in its own way: "performance" means to use "competency". And the latter also define its scope: performance must be matched by corresponding competency!

Furthermore, the prefix *per*- indicates that the required giving of form, or use of capacity required by performance is part of a kind of progression, of progress, of betterment. All men seek to overshoot the limits of the frequently precarious condition that "nature" has provided them with, they all seek to grow, to develop, in fact to better themselves, or even surpass themselves.

This is particularly true when confronted with ill health. It is plausible that one of the fundamental human characteristics of humanity is the capacity to overcome difficulties and obstacles, and to always go further, in whatever form (material, economic, social, cultural, ethical, or even spiritual) that pursuit of betterment takes. The Olympic motto "Citius, altius, fortius" (swifter, higher, stronger), created at the time of the rebirth of the Olympic Games at the end of the 19th Century, could just as well apply to all the manifestations of that human quest. But other constituents of performance make its effects rather more ambivalent...

#### 2. Performance questioned

When attempts to drive back the boundaries never cease, the end result may be that boundaries are ignored. Although it is very true that boundaries cannot be set *a priori*, arbitrarily (history is full of instances of everyday use of what seemed unattainable yesterday), it remains true that, fundamentally, limits are part of the very definition of the human condition.

Refusing to accept this fundamental premise is a denial of reality which can only strike back at those who profess it. The ancient Greek precept condemning hubris and the fevered pursuit of "more, always more", is still as pertinent today as it ever was, for individuals and for society. Overstepping the limits can only be evaluated as a function of the balances which may be disturbed or compromised. In a natural world made up of dynamic forces, the balance is often precarious. If one of the components is blown up and stretched to its limits, the whole construction may be jeopardised, or even brought toppling down, with the risk of unforeseen or perverse effects, leading to escalation and a headlong rush toward possibly dramatic outcomes.

The modern cult of performance is largely connected to the development and sway of technological and instrumental logic, entirely fundamental and respectable, except when it seeks to reduce the rich palette of human experience to the limited criteria of productivity and profitability. This debilitating restriction to a set of figures, constantly needing to be up graded, deprives the issue of any meaning and generates envy and lassitude, since the quest for records and fleeting success is never ending<sup>4</sup>. Furthermore, this is also an opportunity for ruthless economic competition and unceasing efforts for gain and profit. Clearly, there is no call to imagine performance in the abstract without either support or economic impact, but it is unacceptable that performance should become their instrument or their alibi. The human beings involved cannot be seen as instruments in the service of

<sup>&</sup>lt;sup>4</sup> Cf. in particular L. Ferry, *Qu'est-ce qu'une vie réussie?*, Paris, Grasset, 2002, p.19ss. As regards the frequently senseless nature of records, one can refer to the 'Guiness Book of Records'.

financial interests. Ethics commands that naivety be laid entirely aside and that be laid bare the various pretences and manipulations which allow someone to push human beings into striving for records solely to exploit their personal physical resources, under the glare of insatiable media magnification.

Technical and economic considerations also concur with a "liberal" approach to the body with the aim of freeing it from any explicit hindrance, although in fact, it is trapped by implicit ideals of productivity and competition. The social fabric suffers further damage, or is even destroyed and replaced by demands for free access to the consumption of constantly claimed rights: rights over one's own body, appearance, gratification, and performance.

#### 3. Performance, competition, and show

A performance only exists insofar as it surpasses a standard. But a standard can only be defined in terms of an evaluation of the capacities of the average of a given population (the right hand side of the Gaussian curve). The exploit achieved by a performance is therefore always a function of the human context of which it is a part, so that the "performance" of past centuries may seem totally commonplace and uninteresting today. That is why performance is still fundamentally connected to show<sup>5</sup>, and calls for comparison with others, and the attention of spectators. Of course, secret performances, bordering on the intimate, are conceivable. Even so, there is some element of show, except that there is only one spectator; the performer, who displays his exploit for his own eyes alone. This "spectacular" aspect has powerful consequences on the way in which a performance appears and is experienced. It has to be staged, with complex - and sometimes costly - equipment, sites (stadiums, laboratories, technical platforms), institutions (hospitals, clubs, federations, nations,) and powerful information technology (television broadcasts, mass media, specialised media, public relations departments organised like their merchandising counterparts<sup>6</sup>). All this attracts and uses large amounts of money that are increased and multiplied by an array of modern means of communication and display. Show is still at the core of the "cult of Performance" because of the sporting rivalry it harbours, the competition and the opposition between players, which is brandished as the mainspring of the whole operation. Performance does not exist unless it compares to another performance, surpasses it, and in so doing, demeans and destroys it. It does seem then, that linked intrinsically to spectacular performance, there is an element of abasement or even destruction, of others. This ceaseless quest for performance, which is an essential component of an entire society, generates a "culture of outdoing, of constant and destructive competition" where "benevolence as prescribed in earlier times...has been replaced by an obsessive determination - which is seen as positive, or even virtuous – to eliminate rivals in the race to secure the highest positions, in a word to "rub them out"7.

#### 4. Performance and health

We shall not attempt to go into the numerous, various, and complex aspects of all the ethical issues raised by the quest for performance; we shall only mention those which are health related.

Firstly, some of the components of what should be "a good performance" must be reviewed; of what could constitute – without excessive play on words – its health. "True" health is first and always characterised by a form of completeness, of total and, if possible, balanced and harmonious development. This is what, albeit in a slightly utopian form, the WHO definition states: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".

Can we therefore list a few fundamental characteristics of "good" performance as regards health?

<sup>&</sup>lt;sup>5</sup> It is worth mentioning that in English, the word "performance", in addition to the French meaning, signifies an artistic or theatrical performance, or representation of a work of art, so that it is possible to mention – as an avenue for further thought – the existence starting in the second half of the 20<sup>th</sup> Century, of an "art of Performance", the many manifestations of which deserve comparison with the present writings, cf. E. Verhagen, "L'art de la Performance", *Etudes*, juin 2003, p.799-808.

<sup>&</sup>lt;sup>6</sup> Cf. CCNE, Opinion n°45: Ethical questions arising from the transmission of scientific information concerning research in biology and medecine. Report dated July 5 1995.

<sup>&</sup>lt;sup>7</sup> Cf. B.Poirot-Delpech, "Culture de la haine" (Culture of hatred), Le Monde, dated 26.03.03.

It must first of all have a truly beneficial effect on the person concerned, or provide some notable improvement. This benefit is not always easy to evaluate and involves criteria that may turn out to be contradictory. Although the principle of "not doing harm" applies, to ignore it may seriously injure the person concerned. But only that person can assess the advantages and drawbacks – as long as he or she is correctly informed, enlightened, and has the capacity to take a well-founded decision guided by conscience, and is therefore entirely free to choose.

Performance cannot be at the expense of others. Respect for others must always be part of the quest for performance, otherwise it becomes "inhuman" and unacceptable. However, since as we have seen above, the show is its favourite arena, how can we evaluate the underlying motives animating that show? Is there an attempt to rise alone above all others and therefore abase those others? Is there a wish to participate in an undertaking that serves not to liberate others, but to alienate them? Not unite, but divide and exclude? Is not a performance **in the name of solidarity** more socially acceptable? Accomplished within the social body, in particular via the institutions that encompass, allow, and present it, performance cannot be achieved by a violation of the elementary rules which underlie and structure that same social body. Furthermore, rivalry and competition, in many ways the driving forces, are only acceptable within the limits of respect for the rights and dignity of others.

Finally, solo exploits that are reputed to be the concern of a single individual attempting to stretch as far as possible his own limits and potential, cannot be subjected to an *a priori* appraisal of the quality of his commitment. With two reservations, however, i.e. that the commitment be made with full awareness and as the result of enlightened autonomy of judgment; and that it be made in a fully responsible manner so that the social body as a whole does not run the risk of having to foot the bill in one way or another should there be detrimental consequences. Since in fact, no one attains the level of a given performance entirely alone, there can be no question of asking the entire community to pay the price of individual whim.

In even more general terms, it is meaningful that a researcher like A. Ehrenberg was inspired to study the relationship between depression and society after having investigated the "performance society". According to that author, depression is an ailment particularly connected to contemporary modernism that constantly calls for a reduction of "the distance between self and self", and exalts the suicidal notion of surpassing oneself. Depression would then be simply the counterpart of the energy that each individual must summon to attain that improbable self<sup>8</sup>.

## II. Performance, sports and health

The consequences as regards health of the quest for performance in sports activities, bear primarily on three issues: opinions regarding sports and the performance of sports, sports at the top level and competitor sports, and doping.

#### 1. Sports to be encouraged

No one would argue that, within reason, sporting activities are basically constructive. They need to be encouraged and developed, in particular in schools, where for various reasons and in varying degrees from one school to the next, sports are not given sufficient priority.

Everyone would agree that, properly supervised, such activities contribute to a child's harmonious development, particularly during adolescence when youngsters need in a way to re-learn how to use a new body evolving over just a few short months.

Certain forms of competition at that level do seem to be healthy, since they encourage loyal confrontation between individuals and groups who respect the rules of the game while attempting to gain the upper hand. At that level, sport is an education in emulation and confrontation, which is simply a way to socialise, and domesticate or humanise, aggressiveness and violence. Sports are then simply a powerful medium for social integration and a way of transforming aggressive tensions and tendencies in a very positive fashion, on a local level, or in national or even international arenas. This is one of the essential functions of play, and should be fully encouraged.

Encouraging the elderly to build up physical activity or even sports, not just in a spirit of competition, but with the aim of keeping themselves in as good a shape as possible, certainly helps to improve their quality of life. Adults – and this is a truth that strangely enough needs to be asserted –

<sup>8</sup> cf.A.Ehrenberg, La fatique d'être soi. Dépression et société, 2000.

have much more need to exercise their bodies regularly, with reason and moderation, than to take the easier but less efficient option of aggressive medication. It is therefore very desirable that sport should be encouraged, not primarily for performance or competition, but basically as an instrument for well-being, recreation, and elementary hygiene.

## 2. Top level athletes, competitions and records, extreme sports

There are some worrying trends in the way in which sports competitions have evolved in the last few decades, on the borderline between extreme and excessive<sup>9</sup>. The quest for top performance and records, constantly demanding to be bettered, is such that as a result both bodies and minds are thrown off balance. Since it is now almost impossible to break a record to any significant degree, there is a tendency to multiply the number of competitive events and constantly create new disciplines (the triathlon for example has only existed for about twenty years and is a collection of three previously existing disciplines), to evaluate times beyond what is significant (down to a hundredth or even a thousandth of a second), or to vaunt the ever younger age of some participants. To achieve expected results requires extremely strenuous training, motivation and body-building, which is all the more difficult to justify if children are involved. Ingestion of various substances in unreasonable doses may, in the medium and the long-term, be a serious risk to health. Pushed to extremes, this "discipline" leads to doping, as considered below. Early and excessive training artificially fashions and deforms bodies. Of course, it is not easy to assess the boundary between laudable nature and denigrated artificiality, between humanly desirable and humanly unacceptable, between normality and pathology<sup>10</sup>. How can one go about making sure that the athletes themselves or their parents are aware of the benefits and the risks in the short and medium term, so that consequential deformations do not have grave consequences as regards quality of life in the medium and long term, or even life expectancy?

CCNE had already considered this problem in 1993, and was concerned that "the medical problems arising from the practice of competitive sport, or from the initiation into such practice, appear to be numerous. They include effects on growth and puberty, frequent bone and joint injury by micro traumas or by more obvious traumas whose long-term consequences are starting to be known, short-term pathogenic effects in adults..., and the long-term pathogenic effects - still insufficiently well evaluated - of the practice of competitive sports and intensive training. In particular, the effects concerned are vascular risks and bone loss... The risks are greatest in mass sports competitions and high-level sport, especially when intensive training starts early, during childhood, for instance in gymnastics, swimming and tennis"<sup>11</sup>. The situation does not seem, alas, to have improved since that time.

In France, in certain institutions specialising in training for the arts or sports, children have to do, as well as normal schooling, several hours of training every day, so that this questionable system of education puts them through real hardship. Most of them in fact have to stop before they get to competition levels, and despite that, they often find later on that they suffer from distressing physical and/or psychosomatic complaints, and pain. Girls, in particular, experience eating disorders and amenorrhea, very clearly part of the pathological anorexia classification.

Some of these youngsters are obliged to drop sports later on because of accidents due to excessive stress on a still fragile musculoskeletal system. For others, the causes are psychological disorders, amongst which depression is not infrequent.

In any event, even for the best of them, careers are brief indeed, and in Olympic gymnastics, champions of both sexes frequently retire at the age of 18 or 20. Concern for immediate financial gain, sometimes not for themselves, can compromise the future health of these athletes in the medium term. As for the rest of them, they may well join the ranks of the unemployed with the feeling that they have been exploited and that the potentially most creative time of their youth was stolen from them. Many

<sup>&</sup>lt;sup>9</sup> Cf. C.Carrier, "Le dopage en question", *Etudes 3894*, 1998, p.315-322 (p.319s); *Le champion, sa vie, sa mort. Psychanalyse de l'exploit sportif*, Paris, Bayard éditions, 2002.

<sup>&</sup>lt;sup>10</sup> Cf. Similarities in dancing, piercing, or plastic surgery. Some dancing schools have even been described as schools for learning to suffer.

 $<sup>^{\</sup>rm 11}$  Opinion n°35 by CCNE, on Ethics and sport : compensation of hormonal deficiencies in highly trained athletes. May 18th 1993.

will spend their lives suffering from more or less severe physical disabilities because of one or even several serious accidents.

That being so, surely ethical criteria for regulating these practices should at the very least be inspired by the United Nations Convention on the Rights of the Child. Furthermore, any damage to health (present and future), to development, to possibilities of maturing and learning as required for adequate social integration on reaching adulthood, should be prohibited. The process of maturation cannot be completed successfully unless sufficient time is allowed for play and social interaction. Life is necessarily based on interaction, and education must prepare for life in society, for learning different forms of cooperation, and not be almost entirely devoted to competition.

What is true for children is also true for adults. For example, professional athletes must be protected by the rules of labour legislation. "The [present technical and social] context is such that the conditions of performance are becoming superhuman, and perhaps inhuman (increasing difficulty, accelerated pace, shortening of time allowed for recuperation...). This increased burden is jointly encouraged by managers, organisers, and employers" (*art.cit.*, p.320s) <sup>12</sup>. Obviously, this escalation cannot be allowed to continue. Society must seriously reflect on the true meaning of increasingly excessive demands. How to measure a good performance cannot be solved by some simplistic formula; it must be the object of an in-depth review of the values and prospects on which our societies intend to base their philosophy for the present and the future.

#### 3. Doping practices<sup>13</sup>

Doping behaviour can be described as "behaviour involving the use of substances to enhance performance"<sup>14</sup>. At that level, it becomes necessary to fight doping not only because it is a form of cheating and distortion of competitions, but above all because it is seriously damaging to the health of those involved. Of course doping is contrary to the ethics of sports, but the first of our worries must be the protection of physical bodies suffering ill-treatment. Sports are essentially based on the promotion of biological and physical inequality and must not encourage a reduction of that inequality through the use of substances or medications.

Generally speaking, the unceasing quest for an improvement of performance, and the pressure of competition, encourage the steadily increasing use of doping substances to prepare and train athletes<sup>15</sup>. Various studies have demonstrated that up to 60% of athletes participating in competitions do not hesitate, or would not hesitate, to ingest these substances for the sake of winning, whatever the consequences. The dramatic case of former East Germany, gaining medals and titles thanks to the systematic use of anabolisers, is well known<sup>16</sup>. CCNE has already countered the argument based on the difficulty of distinguishing between medication to prepare for an event (or recuperating after the event), and doping as such<sup>17</sup>. It is the health of competitors that must be the prime preoccupation. Real damage to health is involved, and there may be a serious deterioration of life expectancy<sup>18</sup>. J.-F. Bourg also notes that "the life expectancy of former American football players, one of the most

<sup>15</sup> On the various "techniques" used and the pathologies they lead to, cf. M.Rieu, "Pathologie iatrogène dans le sport", *Médecine légale hospitalière 2/1*, 1999, p.13-14.

<sup>&</sup>lt;sup>12</sup> Claire Carrier, opus quoted. And it is noted that in "1905, Petit-Breton rode 25 days a year; in 1946, Robic ran races on 65 days, whereas Hinault ran on 250 days in 1980. In 24 years of professional racing, Henri Pélissier cycled 52000 Kms, whereas Eddy Mercks, fifty years on, in 13 seasons, cycled in the lead for 400000 Kms... The first cyclist was doing 25 Kms per hour, and the champion from Brussels is now at 37 Kms per hour."

<sup>&</sup>lt;sup>13</sup> Cf. in particular J.-P.Escriva, Sport et dopages. Institution de la compétition, idéologie de l'excellence et conduites addictives du sport intensif, Paris 7, 2000 ; P.Laure, Ethique du dopage, Paris, Ellipses, 2002.

<sup>&</sup>lt;sup>14</sup> P.Laure, op.cit, p.41ss.

<sup>&</sup>lt;sup>16</sup> It was only recently, on October 25<sup>th</sup>, 2001, that the Sports Commission of the German Parliament provided for a fund of 1 to 5 million euros, to attempt to cover the medical expenses of the "victims" of this programme. (L.Rigal, *Le Monde* du 28,XI.02).

<sup>&</sup>lt;sup>17</sup> Opinion n°35 CCNE onEthics and sport : compensation of hormonal deficiencies in highly trained athletes. Report. May 18, 1993

<sup>18</sup> Cf. A.Kahn, "Performance sportives et génétique", INSEP 2003

troubled sports, is barely more than fifty-five years, i.e. the lowest longevity of all professions in the United States, and almost twenty years less than the average. American football is particularly competitive, very violent, and matches follow fast and furious..."19. It is likely that not only physical wear and tear is involved, but also abuse of various drugs. As a result, there are certain forms of drug dependence, induced not only by addiction to the products ingested, but also to the fact that if the tough and protective world of competitive sport is no longer there for them, athletes feel lost in a universe devoid of structure.

Furthermore, athletic doping practices are becoming a public health problem insofar as they are no longer the preserve of top level sports, and are spreading and becoming commonplace for ever younger athletes, for whom the media-borne image of sportsmen is increasingly seen as a role model, and who frequently see sporting success as the only way out of a deprived social environment. Frequently, young athletes do not hesitate to take drugs so as to win, at any cost, and escape from their precarious way of life. Their parents, far from discouraging such practices, sometimes put pressure on them to accept demands incompatible with their personal development.

In France, the authorities were worried about these matters and responded, inter alia, by adopting a law dated June 28th 1989, for preventing and repressing the use of drugs in sports competitions, and another law dated March 23rd 1999 (Law no 99-223, M.-G. Buffet) on the protection of the health of athletes and anti-doping measures. The first law prohibits the use of a certain number of substances, and the second one sets up a set of measures<sup>20</sup> aiming to eradicate the scourge. However, despite all efforts, it is an unequal battle: new products are constantly put onto the market, prevention and controls can only be effective if they are international21 and the "pressure" of competitive events is such, that it is difficult to resist. Doping for a competition in fact sometimes corresponds to a feeling of frustration on the part of participants objectively hampered by their constitution or their physical condition, regarding what they consider to be an injustice. It is for this reason that in amateur sports, frequently the less talented athletes are those who use the most drugs. Although this is obviously an infraction against the rules of fair play, this kind of behaviour supports the power impulse provided by the performance, to the detriment of physical and mental health, and therefore to the detriment of the various possibilities of harmonious development of which it is one of the conditions. Furthermore, the perversity of the system is such that champion performers are induced to take drugs themselves so that they can compete with their "doped-up" rivals and keep their top rating. The logic of sports, "let the best man win" is saved, but at the price of everyone's health, present and future.

C. Carrier also mentions "the identity crisis of the non-doped individual in a society 'addicted' to performance"22. Referring to the comic album character Asterix, and his magic potion: "top level athletes keep getting questions about their secret magic potions, quick fixes, and other tricks, ruses, and stratagems... This is the image non-doped athletes are up against; this envious rejection of recognition and admiration greatly increases the difficulty of any anti-doping strategy" (ibidem).

<sup>22</sup> op.cit, p.110.

<sup>&</sup>lt;sup>19</sup> J.-F.Bourg, "Dopage sportif", 18 pages. Many other examples of damage to the health of high level athletes are listed by CNRS Expertise collective, Dopage et pratique sportive, December 1998, p.15-17 ; C.Carrier, "Le dopage en question", Etudes 3894, 1998, p.315-323. It is however difficult to obtain more detail because the sports world is reserved as regards enquiries of this kind. Specific cases of athletes dying during a competition or shortly after reinforce suspicion: Florence Griffith-Joyner, double Olympic champion and world record holder for the 100 and 200 metres, who died aged 38, the cycling champions Ugo Koblet dying at 39, Gastone Nencini and Roger Rivière at 40, Luis Ocania aged 49, Jose Manuel Fuente at 50, Jacques Anquetil at 53, and Jean Robic at 59. In May 1998, the Swiss cyclist Mauro Gianetti almost ended up on this long list, during the Tour of Romandie, after a serious incident involving 12 days under intensive care, of which 3 in artificial coma.

<sup>&</sup>lt;sup>20</sup> Prevention, medical supervision, education, training for prevention, setting up of medical units to fight doping and to give medical assistance to athletes; anti-doping provisions, creation of a Council for prevention and anti-doping activity; listing prohibited activities, drafting of checks and sanctions.

<sup>&</sup>lt;sup>21</sup> The World Anti-Doping Agency (WADA). This Agency is announcing on its site (www.wadaama.org) the adoption of an anti-doping medical code in March 2003 for international federations. The code is to be adopted by the 2004 Olympic Games. Several federations have already approved it.

To overcome such difficulties, several types of action could be undertaken<sup>23</sup>. One of them should be the necessary preventive pedagogical action to inform athletes about the risks. More generally, such information should be made available to society as a whole (parents, children, adolescents, educators, leaders, spectators, doctors...) so as to provide objective facts about the stakes and dangers. For that to happen, totally transparent information on the results of epidemiological studies<sup>24</sup> is needed. Furthermore, it would be necessary to provide new financial and technical resources to monitor the development of substances and medication on the market, and to make pharmaceutical companies insert a marker into doping substances that are presently increasingly difficult to detect. If the monitoring authorities are quite separate from the athletic world, and provided there is no concealment regarding test methodology, it should be possible to identify positive test results. Some of the competitive event schedules should be made easier, and strict deontological rules applied to sports medicine.

However, although such measures should undoubtedly be helpful, they can only become fully effective if they are part of a general reappraisal of the system created by our "performance society".

### III. Medicine, performance and health

Medicine altogether is also confronted with the challenge of performance. This is so in at least two domains: sports medicine as already mentioned, but also medical and surgical performance as well. In both cases, the aim is to make the body as competent as possible to achieve performance. In sports medicine, as we have seen, the medical art may find itself in the service of blameworthy practices, in particular when it seeks to constantly develop and/or use new substances or methods to outwit tests and evade detection. Society never ceases to exert pressure and to sing the praises of therapeutic performance. It no longer tolerates hesitation, nor negative results if they are attended by handicaps or after effects. There is here too a growing demand from society for performance as such.

Outside the sports environment, the medical profession also can be tempted not just by social pressure, but also by the quest for exploits and for technical and/or therapeutic heroics, exploits in medical therapeutic or surgical techniques, and also exploits in medical research. However, healthcare and research must be carefully kept apart. Is it allowable to limit scientific research for the sake of future dubious performances? One would think not. There cannot be standards for limiting research. However, it is allowable to wonder whether, ethically, other avenues of research are available. Perhaps the economic dimension takes first place at this point. Is it for example ethical to launch research in view of practical applications in the future that might be well beyond the financial reach of a majority of people? Any breakthrough is always, initially at least, extremely costly although it may later on filter down to an acceptable market level. Perfecting a technique, or its novel therapeutic use, are not necessarily limited. The real issue is its use for a given person and what this improvement or this novelty can do for that person.

Medicine and surgery have always been based on exploits viewed at the time to be exceptional achievements, but the judgments of contemporary society are easily forgotten. At the time of Starzl's first liver transplant in 1963, of Barnard's first heart transplant in 1967, and the birth of Edwards' first "test-tube baby" in 1978, there were many protests, and sometimes violent criticism, from people who were frightened by this new transgression of a principle of humanity. However, although we must never cease to try and project ourselves into the future, without necessarily being alarmed by the novelty of scientific achievements, there is still the question of the use made of human beings as these achievements unfold.

This may be the case as regards CTA [Composite Tissue Allografts], and particularly limb grafting, and certain techniques for medically assisted reproduction. As for any other performance,

<sup>&</sup>lt;sup>23</sup> Cf. J.-F.Bourg, "Dopage sportif", p.9ss; CNRS-Expertise collective, *op.cit.*, p.27s.

<sup>&</sup>lt;sup>24</sup> As a conclusion to its Opinion no 35 on compensation of hormonal deficiencies in highly trained athletes, CCNE had already noted in 1993: ".. several ethical problems in the field of sport are obviously due to ignorance concerning the existence or non existence of long-term pathogenic effects resulting from the practice of sports, as well as to the lack of scientific evaluation of methods of protecting and curing athletes. Priority should be given to systematic studies of the long-term follow up of athletes".

the intention itself cannot be rejected a priori, but an evaluation of the action itself and of its consequences are worthy of serious attention.

## 1. Composite tissue allografts

Composite tissue allografts represent without question a great and appreciated benefit for a large number of tissues (tendon, skin, cartilage, bone, etc.) Grafting a hand, an arm, or a leg, or even a facial graft (a special Opinion on this subject will shortly be issued) is another matter. Of course, the wish to regain a physical function, the participation of highly qualified surgical units, the development of prior and subsequent research, are all strong arguments in favour of this type of activity. Nevertheless, serious issues must be faced.

The wish of those who are sick or injured to become whole again and recover lost functions is obviously legitimate; however they must be informed that the immunosuppressive therapy that is required comes at a high price, even at the cost of a life. The information given prior to consent must contain these facts, and the risk of a fatal outcome or of uncertainty regarding functional rehabilitation must also be mentioned. It cannot be denied that recent events, giving several people the possibility of leading an almost normal life with good functional rehabilitation, make future prospects seem less alarming. However, unlike the case of organ grafts, where the passage of time improves the integration of limb function, it may worsen the acceptability of immunodepressant therapy constraints, and all the more so because a hand, or a pair of hands, or a leg or both legs, function in plain sight as a result of the conscious will of the person concerned, unlike livers, hearts, or kidneys. Experience of uninterrupted therapy for heart, kidney, or liver transplants, or for HIV contamination, has demonstrated the psychological limits of tolerance to endless medication. It must be clearly stated that young casualties with a graft will be medicated for several decades, which will probably shorten their lives because of premature ageing, accelerated atherosclerosis, vulnerability to infection, and possibly lymphomas or melanomas. The situation will not last for just five years, therefore, but for thirty or fifty years. In this case, the principle of benefaction includes a counterpart of potentially serious harm (shortening of lifetime). To speak of the "ordinariness" of immunosuppressive treatment, as prescribed for other diseases or grafts, is possibly more the expression of a short-term view than an actual ethical reflection, and prevents the true autonomy of the patient from expressing itself.

Can the graft of a limb be integrated into the body image, not just in the short term, but also in the long term? Obviously, the identity of a composite tissue donor cannot invade the identity of the recipient except in the imagination of film makers<sup>25</sup>, but the constant visibility of a most intimate body part, the one most in contact with others, the one most bound up with the emotions, could be the source of alarming schizoid reactions should the graft, once integrated, became separated after a time... Integration or loss of integration arises in different terms for other organ grafts or other composite tissues. If a recipient comes to realise progressively that this is not his own hand, there could be a conflictual situation which would never be the case with a mechanical prosthesis. It is true that in this field, no research has been done at all, that we are very ignorant about the capacity of a human being to integrate "the strange stranger". The tension between physical appearance and its symbolic representation is climactic in this case because of the role of the hand in the general schematic representation of body functions.

1.2. Another matter at issue is whether this is research or therapy. It has been said that autografts are now reaching maturity, and that in this purely surgical field, allografts do not present anything very new, that retardation of the capacity for neurocortical reorganisation initiated by peripheral stimulation seems unlikely, or that at least, the capacity to produce a coordinated voluntary movement based on cortical instruction is improbable; even if one supposes that "it is the hand that makes the brain", and not the other way around, this theory can hardly apply to a graft. On the contrary, some unexpected and encouraging data are emerging: experimental studies have shown, at least with functional MRI, that cortical areas are gradually modified in the post graft time period. It must be noted however that both therapy and research are involved, but in a special way. The singularity is that it is not based on absolute scientific conviction, and also in that therapeutic hopes cannot serve as the basis for research.

 $<sup>^{25}</sup>$  Cf."The Hands of Orlac" silent film by R. Wiene (1923) and remake by E. T. Greville (1960), quoted in " Under the Volcano " by M. Lowry.

Therefore, this is therapeutic performance for which the natural fallout of knowledge concerning human rehabilitation is important, be it for skin grafts in burn injuries, or as regards the physiology of nerve regeneration.

**1.3.** The consequences of third party involvement must also be considered.

Organ donation obtained after brain death is based on the essential principle of anonymity. Donation from a living donor clearly breaks with that principle for the recipient, and sometimes for the donor. A recent recipient actually thanked the family of a murderer who had committed suicide... There is a risk of morbid curiosity, the possibility that the family of the donor would seek contact with the new hand of the recipient cannot be excluded, and this could be the source of fantasies that are all the more potent because the hand is the carrier of more meaning or social symbolism than is the case of a simple organ.

There is also the matter of implicit or explicit donor consent in such a situation. Although it seems very likely that most human beings would consent to donate their liver, or their heart, etc., the imaginary mechanisms involved in the donation of a limb, the hand in particular, are very complex. Should composite tissue graft surgery expand, this dimension would need to be included in questionnaires to possible future donors.

The problem of the cost and of the human and economic resources that such surgery implies is in itself an ethical issue. In view of the fact that the infirmity is not life threatening, that the expected results are uncertain, and that alternative therapy (prosthetics) is available, perhaps arbitration, as a public health decision, in favour of spectacular and sometimes effective therapies to the detriment of other therapeutic investments, needs to be questioned. Decision makers must be aware of the danger that public demand for seemingly spectacular achievements could encourage involuntarily media exploitation.

**1.4.** Grafting composite tissues also raises the question of whether the human body should be repaired *ad infinitum*. This functionalistic, rational, and mechanical vision chooses exclusive functionalism and rejects anything which is not functional. Ethics are there to tell us that life is not entirely function, that life resists, muted and tenuous, in the form of a deep need for humanity, of a feeling that one is not totally master of one's own body, and that respect for oneself is inseparable from respect for others, for one's body, integrity, and uniqueness.

#### 2. ICSI26

As we know, since 1992, ICSI (Intra Cytoplasmic Sperm Injection) is used to introduce the spermatozoa of infertile men directly into a prepared oocyte. This technique, the results of which do not seem to be more of a problem than those of other ART methods, is different in that it has been used for human beings without going through the usual animal experimentation phases, and that it is gradually being extended to all forms of ART.

However, more than the technique itself, it is the introduction of immature spermatozoa into the oocyte that could be viewed as a performance. How much do we know of the long term consequences of gamete immaturity? Are the passage through the excretory ducts and the process of maturation so devoid of usefulness? What of the transfer of nuclei into an enucleated oocyte? Are we still quite sure that the interests of individuals take precedence over the interests of science itself?

## 3. Sexual performances

The creation of the concept of "erectile dysfunction", based on available clinical therapy can only refer us back to a utilitarian concept of performance. Conformity to a model turns sexual performance into a necessity, with persistent confusion between maximalisation and optimisation. CCNE has already published Opinion N° 62 on this subject, and considered that: Pathology, medicalisation, market-oriented thinking, and reference to a certain notion of performance, are the sociocultural characteristics surrounding the launch of the "sexuality drug".

<sup>&</sup>lt;sup>26</sup> Cf. CCNE, Opinion n°75 Ethical issues raised by the development of ICSI of December 12<sup>th</sup>, 2002.

## 4. Gene therapy

Gene therapy is an emblematic example (and one on which the media has focused abundantly) of medical performance. CCNE has reflected on this subject on two previous occasions (Opinions N° 22 and 36). In the space of a few years, rather rash promotion of an omnipotent technique has taken the place of scepticism, and then given way to disappointment in proportion to the hopes raised initially. Several factors combined to make this approach so popular with public opinion: the desperation of those whose loved ones suffer from devastating diseases; the symbolic power of the gene; some degree of medico-scientific naiveté; the involvement of a large number of small biotechnology companies basing their success on this technique; and finally, the taste for self-promotion on the part of some protagonists. As CCNE has been recommending since 1990, we need to adopt a reasonable approach. Gene therapy does not work miracles; it is simply a difficult methodology that is worth developing. It is in fact a logical strategy for certain ailments that are not very accessible to other types of therapy. As for any other therapeutic innovation, there will be disappointments, possibly disasters, that a prudent and lucid approach must seek to minimise. The objective is nevertheless legitimate and success is possible, or even probable for certain well-defined disorders.

## 5. "Therapeutic" cloning

The increasingly audacious techniques to introduce a nucleus into an oocyte, or to change it, continue to fascinate the public. Whatever ethical opinion one might have on the subject of so-called therapeutic cloning, the question of consuming resources harvested from a large number of women for the benefit of one single person, cannot but be raised over and again. The Committee's Opinion n° 57 on the ethical dimensions of collective choices as regards healthcare addresses this point.

# 6. Medical or surgical exploits in general

In more general terms the question of medical and/or surgical performance arises, when it takes on the form of an *exploit*. Although the importance of such breakthroughs is undeniable, it should not be forgotten that they can be short-lived and simply a "flash in the pan", without any genuine future. In medicine, authentic progress is never made up of one isolated exploit. On the contrary it becomes part of a slow and progressive integration into a process of care on a broader, slower, and multifactorial scale. Without that integration, which may well modify the procedure significantly, the exploit may not turn out to be "exploitable" and may even be counter-productive. Great care must be taken to ensure that people are not used more for the institution concerned than for their own benefit. In these matters, "success" is not purely technical. It relates to the somatic and relational life of a person. The complexity of repair cannot be dealt with through simple means; it must take into account the subjective expectations of a person who is sick or injured. Amputation of a part of the body is a major narcissist wound that purely technical repair on its own is frequently incapable of correcting. Quality follow-up on a personal basis, which is never very spectacular, is in the final analysis the most important component of care-oriented medicine.

As regards healthcare, therefore, the prominence given to innovation and exploits raises the issue of where we stand on care procedures of a more habitual or even routine nature, that are nevertheless a decisive element in the global response to demand for care. We cannot deny that there is little inclination to recognise the exceptional nature of this kind of care, both humble and profoundly human. Our system of values seems to be more responsive to extremes, to practices at the borderline of what is possible and allowable, where records are broken and perhaps transgression combine to confer prestige and an image of power on initiatives that no one bothers to question the usefulness of... The impression is given that scientific and therapeutic breakthroughs can no longer submit to the sometimes slow and uncertain process of acquiring knowledge, and that procedures hitherto considered sound practice are apparently outdated when there is a need to respond to what is deemed

 $<sup>^{27}</sup>$  The lexical proximity of the words "exploit", "to exploit" and "exploitation" are notable: any exploit needs to be exploited... sometimes through the exploitation of others.

an emergency. What we would sometimes see as chancy or a little hasty, finds justification that does not tolerate criticism: urgency, individual rights, freedom of research, and so forth<sup>28</sup>.

In view of the above, the monitoring and supervision of innovative biomedical activities should be regulated, the consequences of actions undertaken should be anticipated and studied, and as a result, principles should be established to preserve the values essential to all healthcare.

Individual motivation, and also cultural and social encouragement for achieving medical and surgical exploits deserve some mention. Individual motivations resemble those of other performance seekers: do something out of the ordinary and therefore become visible to self, to peers, to fellow citizens... and to those holding the purse strings. Cultural and social encouragements are of the type analysed in the National Consultative Ethics Committee's report on science and the media<sup>29</sup>. One of the *raisons d'être* of exploits is to get media attention, and professional media players are on the alert for media-worthy material, to the extent that they are sometimes tempted to manufacture it.

These motivations interact in a society which generates performance and exploits and states that it wishes to confer value on them. A levelling of cultural standards the world over, and uniformity of life styles, raise with increasing sharpness the issue of personal individuality that is all the more essential because – and that is the core of paradox – individuality is the central value in our uniform society. Society's criteria for evaluation are all more or less confined to performance, if not to exploits. To achieve them therefore is to obey the injunctions of a dominant cultural model, and in spite of the latter's capacity to level any differences, to seize some degree of visibility of which most of us have a vital need.

### **Conclusion**

Our modern and post-modern societies, fundamentally inspired by the quest for performance, do not always explore their implications and consequences. As regards health, in particular, the effects are sometimes pernicious, in particular sports because of doping, or in the field of medical technical innovation, so that the following recommendations seem pertinent:

- A serious and methodical <u>evaluation</u>, with publication of results, of the medical and social consequences of these practices. CCNE is now renewing this request, which was first formulated in Opinion n° 35 of May 18<sup>th</sup>, 1993. It is unacceptable that, more often than not, one has to be content with information obtained indirectly, and that certain facts continue to be unspoken or concealed. The first demand is simply to know, whereas more often than not, to quote a professional, "we know nothing".
- A lucid awareness, and therefore the clearest possible analysis, of the economic and financial conditions and constraints at the source of excesses presently tolerated in sports for the sake of show, and in research in the name of profitability. Under the disguise of freedom for performers, they are frequently instrumentalised.
- A critical approach of the relationship between economy and performance. Performance can mean innovation, patenting, appreciation of research, all of which are obviously driving forces. But the question of freedom of research remains unsolved if that research is bound by the need for excessively early returns on investment and above all, by its purpose. If medicine becomes only an outlet for an increasingly greedy market in the name of innovation, it will be to the detriment of mankind. It is obvious that major financial interests are behind doping in sports. Why should we assume this is not the case for certain medical performances? The quest for performance as an end in itself cannot be disputed *a priori*. Efforts to give reality to a hope or a dream or unrelenting attempts to improve unsatisfactory human conditions, are entirely legitimate.
- Recognition in all domains of the fact that there are <u>limits</u>, those of the human condition, and that if they are transgressed, there will be a threat to the fragility and the vulnerability of those directly involved, and therefore to their dignity. Not only is

<sup>&</sup>lt;sup>28</sup> (E.Hirsch), "Information médicale face à l'innovation et à l'exploit cellule de réflexion de l'Espace éthique du 16 décembre 1999", in : Ethique et soins hospitaliers Espace éthique - Travaux 1997 - 1999, Paris, AP-HP/Doin, 2001.

 $<sup>^{29}</sup>$  Opinion  $^{o}45$  by CCNE Ethical questions arising from the transmission of scientific information concerning research in biology and medecine, dated May  $31^{st}$ , 1995

the health of a person destroyed, but also in social terms, an immoderate cult of performance leads to the glorification of some and the humiliation of others, or even their exclusion. However, these efforts and this research also come up against the fundamental limits of the human condition. Such limits cannot be set *a priori*. But they do exist, as a sign of both our essential need to relate to others (the limit is in fact the dignity and rights of others) and of our mortality. Fragility and vulnerability are part of our make-up. To accept them is part of the dignity of being human, and is probably just as much of a "performance" and health giving as any exploit under the sun. These themes are illustrated by doping in sports events because, "cheating" is a warp of one's relationship to others. Although, usually, doping does not stem from the desire to dominate, it does display a desire to attenuate biological deficiencies in a competition and in doing so, makes it an unfair competition. Therefore, not only should we aspire to sports without doping, but also to develop in those sports a team spirit, and the forces of civilisation, and the sense that rules and adversaries must be respected (i.e. fair play), for all of which dopeless sports are also a favoured vector.

Notions of performance and exploits must not be confused with those of rivalry and competition. No equivalent should be drawn between cheating in sports and immoral conduct.

To sum up, the quest for performance, which is an integral part of our humanity, must not blind us to the conditions of its attainment, particularly in the case of sports events and medical research for which the first and fundamental significance is, and must remain, that it magnifies the value of the physical, intellectual, social, and moral dimensions of humanity.

The issue of personal autonomy must never be left dormant. Be it in the field of doping in sports, or consent to audacious medical procedures, the economic, ideological, social or psychological workings of subjection are – alas – well known. We must always be aware that the fervent quest for performance driven by an imperious desire to make progress, can mask the most constraining of alienations.

It is to be hoped that awareness and serious evaluation will lead to prudent and responsible behaviour, and if necessary, to rules of good conduct.

November 17th, 2003