

Consent for the benefit of another person

N°70 - December 13, 2001

Contents

[I. Problems raised by scientific and medical practice](#)

[II. Legal considerations](#)

[III. Ethical considerations](#)

[Conclusion](#)

Consent given by a person to diagnostic or therapeutic procedures for research or medical or surgical treatment, is one of the essential foundations of the relationship between physicians and patients. However, in some cases treatment or research is less in the interest of the person concerned (i.e. the "index person") and more in the interest of another person, or persons (i.e. "third party", as compared to the primary relationship between physician and patient). When the interests of a third party are involved, consent given by a person, even if it is only to some minimal disturbance, is significantly altered because pressures could be brought to bear in the interest of the third party. Consent in favour of, or for the benefit of a third party, leads to several principles, possibly conflicting, being considered : the autonomy of the index person, benevolence in favour of a third party, and solidarity. These principles are in perfect harmony if consent is fully protected by all appropriate rules of freedom and information, if optimal care is nevertheless available, and if both parties agree on the joint benefit for them of such investigation or treatment. But there may be cases where there is a conflict of interest between the index person and the potentially benefiting third party or parties. Consent may then be denied.

In any society there is a latent conflict between individual rights, what we owe to others, and the rights others have over us. Among the first of these, are the social constraints expressed by the existence of mandatory measures. Balancing rights and obligations is the principal object of the social contract on which States are built. The general object of law is to make that balance effective.

In many cases, there are no written documents to eliminate the disunity between individual rights and duties to other, but even when such documents apply, ethical tensions subsist and deserve analysis. In that connection, the issue could arise of a person being asked to consent to an intervention to which he would be subjected, not in his own interest but in that of another person.

Situations vary ; they can be classified into two categories. In the first of these, consent may be experienced as an act of benevolence or of solidarity, in favour of a particular individual to whom the person concerned is connected, as in the case of organ transplant from a live donor. In the second category, a third party may claim a right - apparently a legitimate one - to request an intervention on someone else. This Opinion will be discussing such situations, where the rights of different parties are in opposition. If one considers that the principle of autonomy must prevail over the principle of benevolence or of solidarity, is there not a risk in cases where damage to the body of the index person would have been minimal and in no way hazardous, of depriving the third party of a comparatively very important benefit ? If on the contrary, following a consequentialist or even opportunistic view, one considers that the principles of benevolence or solidarity should necessarily lead to giving primary consideration to the interests of the third party, then the risk is of exerting excessive pressure over the index person to the detriment of rights and liberty.

In this connection, CCNE was required to consider the specific case of sexual assault, in which a person in police custody is asked to consent to HIV screening in the interest of the

victim. This referral is far from signifying conflict of interests situations ; it is based on a radical asymmetry which could seem, at first sight, to go against common sense. We are confronted by a claim based on the principle of autonomy in the presence of a traumatised victim. And yet, this referral, in spite of its singularity, has led to extending reflection arising out of scientific and medical problems linked to present practices, to a certain number of other very different situations which are nevertheless connected by the fact that they all raise the same ethical issue of consent for the benefit of another person.

I. Problems raised by scientific and medical practices

Increasingly, medical practice uses screening procedures, involving either direct or indirect markers of infectious, metabolic, and genetic diseases, or imagery. These investigations are not limited to the person concerned. In the interest of that person, they may sometimes lead to research on other people. The issue of consent for the benefit of another person may therefore arise in a wide variety of situations, whenever the health of a third party comes to depend in varying degrees on another person. Situations vary considerably as to seriousness but the problem remains of whether, when there is a conflict of interest between two people, one of them should take precedence justifying interventions which could mar freedom of consent.

The particular case of informing and requesting consent when engaged in scientific research without direct benefit, is quite another matter and has already been the subject of several CCNE statements, in particular in Opinion [n° 58](#) ("Informed consent of and information provided to persons accepting care or research procedures").

II. Legal considerations

Intervention on the human body by a physician is subordinate to two conditions : consent to the action and therapeutic finality.

The requirement for consent rests on the fundamental and age-old principle that the human body is sacrosanct, justifying and ensuring protection of the integrity of a person and of that person's body. This principle was included in the Code Civil by article 16.1 following the bioethics laws of 1994, and a complement is to be found in article 16.3 which gives general acceptance to the need for obtaining consent, before any intervention. But consent alone is insufficient and to it must be associated therapeutic need to initiate medical intervention. This was broadened in 1999 to the notion of medical necessity, which obviously means in the interest of the patient, in the new draft of article 16.3 in the Code Civil. An emergency is the only exception to obtaining consent, again in the interest of the patient, when the patient is in no fit state to give consent.

The social and historical context explains the importance attached to consent. Evolution in the attention devoted to it is visible in various international documents: The Declaration of Helsinki of 1964, several times revised with the latest version in 2000, the International Covenant on Civil and Political Rights adopted by the United Nations in 1966 and ratified by France in 1981, the Manila Declaration of 1981, the Declaration on the Promotion of Patients' rights in Europe in 1994, the Convention on human rights and biomedicine signed in Oviedo in 1997, the Universal Declaration on the Human Genome and Human Rights in 1997. The WHO Declaration on the Promotion of Patients' rights states that "The informed consent of the patient is a prerequisite for any medical intervention." In France, consent is an important component of the Huriet-Sérusclat law on the subject of biomedical research, and it was enshrined in the bioethics laws of 1994. Consent, founding principle of intervention on the human body is an obligation imposed by respect for individuals and the expression of one their fundamental liberties : the right to refuse. Constant jurisprudence emphasises the need for consent to be informed so that the freedom and the dignity of the patient can be respected, thereby encouraging increased autonomy. Consent also appears as one of society's achievements which deserves protection.

status, to use assisted reproductive technology (ART) with the aim of reducing cross-contamination within the couple. Technically, there is a similarity with sero-discordant couples in which the man is sero-positive, and recourse to ART methods such as IVF or ICSI may be justified. The May 10, 2001 ruling should be modified so as to include couples in which both partners are HIV-positive for access to MAR, if the case arises. The notion of consent is a corollary to the information imparted to the patient, which is a legal obligation for physicians, codified by specific legislation. Since the sick person may "reject any investigation or therapy", the information supplied must of necessity be adequate to enable enlightened consent. This means that information must be delivered with a view to obtaining consent unencumbered by any form of constraint. The normative framework of the usual physician-patient relationship is somewhat obscured when interventions on the human body for therapeutic or diagnostic reasons are no longer performed in the interest of the actual patient, but in the interest of a third party. Insistent pressures created by third party interests and increasingly evidenced by scientific developments, are now distorting the system and in practice the concept of "consent in the interest of a third party" is appearing.

It is true that the interest of others had already been taken into consideration in the past, in particular as regards blood and organ donation. The 1994 bioethics laws also took into account new techniques of intervention on the human body emerging from scientific progress, by extending the notion of therapy to include medical interventions for the benefit of a third party (sampling of tissues, products, cells, organs, and medically assisted reproduction). In all such situations where the interest of a third party conditions intervention on a healthy person, the need for consent remains sacrosanct. In order to protect the person concerned, lawmakers have added special conditions to procedures for obtaining consent : it must be written, or even be an instrument drawn up by a notary, with the possibility of retraction at any time. In certain cases, non compliance with these consent procedures is viewed as a criminal offence.

An analysis of the law reveals that the rule regarding the inviolability of the human body does not prevent action - viewed as legitimate - affecting the body, according to conditions set by law.

Legislators have listed a certain number of situations in which medical intervention is mandatory, for reasons of public order or health. However, even in such cases, the value attached to consent is so substantial that it is accepted that no physical constraint may be applied. The only consequences of refusal are legal or criminal proceedings. In such circumstances, to the information already described above must be added due warning of the legal consequences of refusal.

This is the case for mandatory immunisation as listed in the code of public health (diphtheria, tetanus, poliomyelitis, tuberculosis) for reasons of public health, and there are legal sanctions for non compliance. Punitive sanctions (for reasons of public order) are applied in particular if there is a refusal to submit to therapy for drug abuse, to blood alcohol level testing when drunkenness is suspected, or if social and judiciary monitoring procedures are rejected in sexual assault cases.

Investigation measures ordered by the judiciary authorities have now been formally established for the collection of genetic prints. In the field of identifying genetic data, there would be consequences attached to refusal to submit to enquiry or investigation procedures instituted for the purpose of finding evidence for, or refuting liability or filiation. In the civil courts, refusal to submit to investigation limits the powers of the judge, but on the basis of articles 10 and 11 in the Code of civil procedure, he could draw conclusions from abstention or refusal. In the criminal courts, refusal to submit to sampling, or by the same token refusal to have fingerprints taken, if there is any trace of physical violence, could be reason to sue for rebellion according to the provisions of Articles 433.6 and the following of the Code Pénal (Criminal Code).

Finally, mandatory HIV screening is a fact, for reasons of sanitary safety, since it is a condition for blood, sperm, and organ donation.

In all the above cases, constraints in the name of public health or public order limit personal autonomy. But they essentially concern situations where no third party is involved. When a third party is identified, ethics must play a new role.

III. Ethical considerations

The urgency and the gravity of a situation when a third party is exposed to risk, the intrusive and invasive nature of investigation and therapy are as many entirely different situations which must be carefully considered. There is no singular third party but a variety of parties and situations, and differences must be considered each in their own right. None of the arguments presented - urgency, gravity, invasiveness - can be viewed as a classification.

The screening procedure to be performed may concern the index subject, but also others, i.e. the "third parties" who are the subject of this Opinion. This is the case of certain transmissible infectious and genetic diseases. Discovery that a person is a carrier for an infectious disease may have direct bearing on the need to screen another person who may have been exposed. This is the case for example in the event of rape, or exposure of a healthcarer to contamination by blood. In the same way, an epidemiological enquiry because of the discovery of a transmissible disease may justify examination of a third party to identify the source of contamination and take possible protective steps. In other cases, in the event of genetic disease, searching for a mutation in the family of the index person may be justified by the possibility of potentially beneficial preventive measures for screened relatives. The increasingly prevalent notion of "familial" disease can be the source of conflicts within a family which need to be recognised in order to prevent them. Whether in the field of organ or tissue grafts, and maybe in the near future of embryonic cells, the tendency to consider that a human being may be seen as made up of elements constituting a source of reparation for others also raises the question of a third party's best interests. Finally, a totally different situation, but which may well be viewed as belonging to the same category, is the case of a caesarean section, which may be medically to be recommended in the interests of the child, but not accepted by its parents. These examples are in no way an exhaustive list of possible situations. Generalisation is as much to be avoided as oversimplification.

Consent relationships, which used to be viewed as a binary type relationship between two people, are necessarily altered when intervention is requested on behalf of someone else, with a third person intervening. The latter, more often than not a physician, may initiate or participate in the request (for example in the case of organ grafting), or be asked by the claimant to intervene and obtain consent (for instance in the case of screening for HIV infection when there has been sexual assault).

In any event, the role of that person goes beyond simple intermediation since he plays a key role in obtaining consent for the benefit of a third party. His analysis of the situation, both medical and ethical, must strive for completeness and be particularly meticulous as regards the quality of information owed to all the parties. No shadowy areas must be allowed to subsist and be the sure source of an aggravation of possible conflicts at a later date.

The various examples described below are not (and cannot) be exhaustive. Fruit of - for the most part - recent scientific developments, these situations differ greatly and should not lead to a single response. They have been grouped into three major considerations : the implicit nature of the donation, obtaining agreement, the limits to the will for benevolence.

1. *The implicit nature of the donation.*

By defining it as "the transfer of a physical or moral possession to another person without counterpart" , the donation, "akin to sacrifice" in religious parlance, (...) in secular terms, is defined in contrast to trade, purchase, or sale, since it supposes an absence of compensation or condition. It is an expression of generosity, giving away and complete availability of that which is given. To have a gift or be gifted, signifies benefiting from the generosity of fate" . In such circumstances, it is the expression of an act of solidarity where

the spirit of donation implies that consent is given fully and without restraint, altruistically; it may however on occasions be only implicit or presumed. In the case of organ grafting when the source is a cadaver, this would seem to be the case.

In cases where a person is in a state of brain death, care to that person is not in his interest but only serves to keep organs as healthy as possible so that they can be used for a graft. This is typically the kind of situation where care is given solely for the benefit of someone else. Strictly speaking, it is only if and when a person has expressed agreement that sampling should be allowed, at which point that gift is pure generosity. When it is implicit, consent is presumed according to the definition which legislators decided to keep as part of the 1994 Law (law 94-654). The fact that it is possible to expressly refuse to do so by recording it on a special national Registry, as provided by the 1994 Law, reinjects the notion of altruism into presumed consent.

2. Sometimes, rather than consent, assent is requested for the benefit of a third person.

This could be a group of situations in which, between a request for solidarity expressed to the person concerned and the recognition of the autonomy of a third person, society can be described as an element of mediation attempting to reconcile two sometimes separate viewpoints. By its very nature, a request for consent cannot be forced, but there is no denying that seeking that consent may occasionally be subject to undue influence. This could be the case should some viral infection be contracted in a healthcare institution, in the case of HIV screening of patients if a healthcarer is injured, in the event of a conflict of interest between doctors and parents concerning born or unborn children, as in the case of a caesarean section, or the very special case of an HIV infected perpetrator of sexual assault in police custody.

- The case of viral infection contracted in a healthcare institution.

It may happen that a patient who has spent some time in a hospital or has had some medical examination (such as endoscopy...) is found to have some viral infection, hepatitis B or C, or HIV, and the source of the infection is another patient, or even a healthcarer. The enquiry which will be made to prepare the way for remedial measures (medico-legal reparation, technical preventive measures for the future such as sterilisation of medical or surgical equipment...) would be based on samples taken to find the potential source of infection. Those concerned may therefore be approached so that samples for the benefit of a third party can be made.

No systematic screening procedure has been established for this event. There is an ethical problem in so far as there may be a conflict of interests between the legal compensation legitimately claimed by the victim and the determination of the source of contamination. CCNE, in a very specific case, was consulted by Minister Bernard Kouchner in May 1999 about a case where HIV or HCV contamination was discovered after a hospital stay in people who had been sero-negative for these viruses before they were admitted to hospital. In its response, CCNE suggested that a clear separation be made between the notion of traceability required for an epidemiological enquiry and possible issues of the liability of a patient or healthcarer, so as to avoid a connection between carrying the virus and possible liability, and to avoid immediate rejection of an enquiry.

- HIV screening of patients if a healthcarer is injured

It often happens that healthcarers hurt themselves while they are taking a blood sample from a patient whose serological status is unknown. Taking preventive medication, which is not devoid of serious side effects, will depend here again on the patient's serological markers. If the patient is conscious, consent can be given. Otherwise, tacit consent becomes an issue.

It is thought by some that a relationship based on tacit trustfulness combined with an emergency situation speaks in favour of systematic screening. In the case of a healthcarer who has suffered an injury while taking a sample from a patient, the a priori trustful

relationship which exists between carer and patient is such that consent is implicit. This concept of implicit consent as a corollary to a trustful relationship between carer and patient, would also prevail when a patient is injured by a carer.

It is a fact that if the patient is conscious, he would not be any more likely to refuse a sample than any other medical attention, unless he was refusing all healthcare ; if the patient is unconscious, one must suppose that consent is deemed to have been given for that action as for any other necessary care. In this latter case, the fact that action is urgent gives the physician leave to act while informing the patient's relatives. This involvement of relatives was discussed by CCNE in Opinion [n° 58](#) saying that "families are not legal representatives. They cannot consent to care in a patient's name. The Code of Medical Deontology (Article 36) simply requires them to be 'notified and informed' (Art. 36). It does not say they should be 'consulted'." In the circumstances, health care providers take decisions as long as patients are not in command of their mental faculties. Furthermore, medical rules of confidentiality are such as to justify test results not being communicated to the family.

It is however true that, in certain cases, strict compliance with respect of personal autonomy has led to waiting for the patient's consent despite an emergency situation.

-The issue of conflict of interest between doctors and parents of an unborn child regarding a caesarean section

Such situations are certainly infrequent, because in this kind of situation the future mother rarely refuses, knowing that the life of the unborn child is at stake. However, certain cultures refuse a caesarean section although the physician considers it essential. Can a woman's rejection of an essential procedure be overruled by force ? Can the principle that the human body is inviolable be transgressed in the name of saving another life ? It is in this kind of distressing emergency that the conflict appears to be most acute. Answers to the question depend on the way in which the birth of the child and the relationship between doctor and mother are considered. In the situation where a caesarean section is objected to, it becomes of capital importance to determine who takes the final decision.

It is possible to consider that the aim of the caesarean should be to save two lives. In practical terms, the trustful relationship between doctor and patient and information imparted using all available scientific and cultural communication resources should be adequate to make the interest of the child sufficiently clear so that it is not necessary to exert questionable pressure. A state of emergency may however lead a medical team to privilege saving two lives rather than one.

- Screening the perpetrator of sexual assault for HIV infection while in police custody.

The potential risk of transmission of infectious agents (HIV, hepatitis B) by an unknown or identified sexual aggressor, is justification enough for a physician to prescribe antiretroviral preventive combination therapy immediately. It is important in such a situation to find out as soon as possible what is in fact the HIV status of the person in police custody, so that preventive therapy for the victim can be stopped urgently in view of the serious - sometimes dangerous, or even lethal - adverse effects. This request involves a blood sample from the aggressor, and therefore requires his consent.

If that is the case, he is presumed to have freely given informed consent. The law states the rights of a person while in police custody and in particular there is the right to be seen by a physician and to speak to a lawyer immediately. The physician, present at the behest of the public prosecutor or upon a request made by the detainee himself, may be required to inform and convince the detainee that there is a need to be sure of his serological status in the interest of the victim, and possibly his own interest, although he has the right not to be informed of the results.

This blood test in the interest of a third party must preserve medical confidentiality, which in this particular case is obviously limited. In fact, although the results of serology should be covered by medical rules of confidentiality, and therefore known only to the physician, the advice which he may give the victim to stop or continue treatment, enables the victim to draw conclusions. The results of the blood sample, which were not requested by any legal

procedure, and which at this point are only useful to the victim's health, should be allowed to remain separate from the inception of legal proceedings because of the need to safeguard medical confidentiality. They should not lead ipso facto to communicating the serological status to the prosecuting authorities. It should be possible to restrict such communication to whether the test was accepted or refused.

Should consent be withheld, the sample cannot be taken by force since this would theoretically transgress the principle of non-violation of the human body and in practical terms, it is almost impossible to do so. Although in fact refusal is rare (about 5%), this leaves unanswered the question of whether such rare situations should justify obtaining consent through pressure in all cases. Can one accept that, because of urgency, rights of victims prevail over the rights of aggressors? The law is equal for all citizens, and the law cannot recognise primacy of rights.

In ethical terms, at first sight, the radical lack of symmetry of the situation may appear as added violence inflicted on the victim. Requesting consent from the detainee for a minute and harmless procedure appears ludicrous to victims of assault who must furthermore submit to cumbersome emergency therapy, which may be pointless, and which they would much prefer to stop. Is this not pursuing to absurd lengths the consequences of a principle which paradoxically becomes harmful through these extremes? It is surely unacceptable that by not knowing the serological status of the aggressor, the victim is obliged to continue a potentially dangerous and pointless treatment. And is it not just as unacceptable to allow such injury to be added to rape?

In fact the situation is not so simple. First of all, experience shows that almost 95% of aggressors accept quite naturally what is asked of them, and all the more so because they are under arrest and apprehensive. Because of the 5% who express a choice which penalises the victim of rape, should they all be denied, after at least a summary exchange of information, the right to exercise a voluntary decision which paradoxically redirects them into a position of shouldering responsibility and realising the true gravity of what they have done? Belittling aggressors does not help to protect victims. The common interest of both parties is that screening should be offered at the very outset of police custody so that it can be performed at once and in the best possible conditions. The aggressor must understand the purpose of this sampling, and the victim must be made aware of results as soon as possible. If the suspect continues to refuse consent in spite of the information given to him, this refusal will be made known to the judge who will be able to draw whatever conclusions are appropriate.

There is one final problem. Excessive enforcement of the law on presumption of innocence should not be allowed to delay blood sampling the aggressor. This would be an aggravation of the prejudice suffered by the victim. The new law which permits the presence of a lawyer for the defence from the outset of police custody should make it possible to set up a system for emergency screening in acceptable conditions and with medical assistance. Medical confidentiality must apply whether the detainee is innocent or guilty. Any delay in this procedure could have serious consequences.

3. Finally, there are cases where the will for benevolence means that although both parties must be respected it is not possible to draw final conclusions regarding the primacy of the expression of solidarity on the one hand, and autonomy on the other.

In such cases, the decision making process is the most difficult and there has to be detailed analysis on a case by case basis in an effort to seek both justice and meticulous assessment of the situation. This may be the case for communication of genetic information, organ grafting with live donors, and problems arising out of the broader conditions attached to a pre-implantation genetic diagnosis.

- Communication of genetic information

Transmission of genetic data regarding a person for the benefit of a third party (blood-related member of the family) may be requested to obtain a complement of family genetic

information and a clear specification of anomalies, for systematic exploration of mutations in a family starting with the index case, to evidence a genetic risk for which prevention may or may not be possible.

Intra-family genetic studies therefore are concerned with the communication of genetic data by a person, for whom genetic tests have revealed that he or she is a carrier of a mutation generating a disease, to other members of his or her family so that they too can be investigated for this mutation. In this case, the third party is totally identifiable and biological relationship with the subject is an established fact. The third party's interest could be to be aware of his or her status as regards this genetic anomaly, and therefore be in a position to initiate preventive monitoring or submit to curative therapy, or else choose not to transmit the anomaly to descendants.

This circulation of information to family members may exceed the boundaries of legal relationship and also concern biological relationships which have not been legally consecrated. Assuming the legitimacy of such circulation of information to the family, there is a clash with another kind of legitimacy embedded in law, i.e. the right to privacy and free will. Personal genetic data is doubly protected : since it concerns an individual's health, it is protected by medical rules of confidentiality, and since it is within the realm of an individual's privacy, it is protected in the same way as all other personal data by the right to privacy which is embedded in the Code Civil.

For ethical reasons, members of the family can only be approached by the subject himself and not through the physician who cannot divulge privileged information. Therefore, when it is in the family's interest, because of the genetic risk discovered in one of its members, medical practice calls for systematically suggesting to the person concerned that he take on the task of revealing this genetic anomaly to other family members concerned, but with no obligation to do so. If this person refuses to communicate the results of genetic testing he has undergone to other members of the family, the physician cannot warn them of any possible risk. Representations arguing in favour of family solidarity over secrecy may be exposed to the person concerned, but solidarity is no way mandatory. In a majority of cases, consent is obtained without any difficulty, but the person concerned may choose secrecy. This may be dictated by conscience for reasons which must be respected and which may be viewed as legitimate. This may be for fear of distressing those concerned and the wish to preserve the right of others not to know. CCNE had expressly considered this situation in Opinion [n° 46](#) dated October 30, 1995 "Genetics and medicine : from prediction to prevention": "... almost constitutional frailties of an innate and non accidental nature, the interpretation of which for the representation of self and the consequences for present and future life may be of major importance". There may also be a refusal to reveal genetic predisposition to an incurable disease for which there is neither treatment nor prevention.

In that case, the physician is in a peculiar position of responsibility. Respect for an individual's autonomy, freedom of decision, and protection of privacy, are opposed to the principles of solidarity and benevolence towards other members of the family who could benefit from knowing their genetic status. This is a major ethical conflict for a physician. If refusal is expressed, he cannot inform other members of the family of the risk of developing the disease or transmitting it to their children. He is bound by the imperious duty to protect privileged medical information from third parties. He ought to persuade his patient, but the law forbids him, and rightly so, from communicating genetic data to third parties except through the index case. In the previously quoted Opinion [n° 46](#), CCNE reaffirmed the particular nature of this data which contains both elements constituting the individual as a unique being and those which relate him to his family; past, present, and future. Ethical analysis must take this dual nature into account. When the discovery of a genetic anomaly entails considering biological sampling for other members of the family, their interest (third party) may be legitimate and to be opposed to the determination for concealment of the individual carrying a defective gene.

Since that Opinion was discussed, there has been no significant change in substance, even though there is, in a fairly general movement of opinion, increased pressure in favour of the principle which one might designate by the term of "normative solidarity" prevailing over the sanctity of the right to privacy. This conflict appears to be divisive. Although in the immense majority of cases, the quality of the relationship between the medical professions

and those from whom samples would be taken, on the one hand, and a sense of responsibility on the other hand, lead to consent being granted without dispute, there are some special intra-family situations, when doubts are expressed by one person about the validity of a relationship, and there is reluctance to invite any mention or attempt at elucidation by anyone at all, so that consent is refused. This refusal of consent may be very understandable in cases where genetic screening would not lead to preventive measures being taken but would simply further knowledge of someone's status.

- The case of the living donor

There is finally the ever difficult issue of organ donation, from a living adult or under-age donor. Legally, the matter is settled, but in ethical terms there remains the issue of freedom of consent.

The case of the living donor is very strictly regulated : law 94-654 dated July 29, 1994, fixed very stringent limitations to transplantation with a live donor in the specific context of the intra-family environment.

For reasons directly connected to obtaining free and informed consent, no transplant material can be taken from an incompetent adult nor from minors, except that for the latter, bone marrow donation is authorised between siblings. Another person, holding parental authority or legal representative status, gives authorisation. Here autonomy is sacrificed in favour of benevolence. It is because of the unusual nature of the situation that supplementary legal precautions are taken : expression of consent is made in the presence of a magistrate and a committee of experts authorises sampling. In a written communication dated March 27, 1998, CCNE offered two possibilities : the first of these was broadening to some extent the categories of possible donors within the family and between non-related individuals ; the second dealt with the mode of operation of a regional committee of experts, in particular that a refusal to grant transplantation authorisation would need to be motivated.

- Even in the case of related living donors, some undeniable ethical issues subsist. Freedom of consent is sometimes impaired by deliberate - or implicit, or even supposed - pressures from relatives and friends. When the health or even the life of an ascendant, descendant, or relation are in question, and their fate hangs on the decision of a member of the family, can one consider that the latter is totally free in taking a decision ? Accepting to donate depends on a number of contradictory considerations : the wish to help a member of one's family, with the family's opinion in the background, and the anticipation of possible loss of body integrity. The donor carries within him the source of treatment which in some cases will have detrimental effects on his own body, but which will be salvation for someone who is nearest - maybe not dearest - to him. Finally, the role of the doctor, who is the mandatory intermediary in this situation of consent for the benefit of a third person, cannot be eluded. He must, paradoxically, run the risk of "putting in peril one of the fundamental and founding principles of sound practice 'do no harm', by neither excess nor default" . To avoid both undue pressure and harmful disorders (of the psyche and of behaviour in particular) in the donor, in depth reflection should be initiated at an early stage and far ahead of the expected date of transplant , so that the potential donor can be protected and helped to accept his own decision to help, at the time it is taken and later, without prejudice to generosity.

- A living donor transplant, particularly an under-age bone marrow donor, may be too young to either understand or usefully express an opinion.

This reinforcement of safeguards is compensation for the weakening of consent procedures : in the extreme case of a legally and de facto incompetent minor, encroachments are cumulative since consent is not given personally and yet seriously commit the integrity of the donor's body.

In these intra-family organ donation situations, between spouses, or from parent to child, family pressure to consent, or in some cases the strong emotional bond between the two

people concerned, the burden of guilt if consent is withheld, are all formidable distortions to the expression of authentic consent.

- Questions of a similar kind may be raised by a pre-implantation diagnosis practised for the benefit of a living child (which would require a broadening of the present scope of the law). This subject has been referred to CCNE and a specific Opinion will be published.

Conclusion

The broad variety of forms of ethical tensions originating between two essential demands, autonomy and benevolence, has been evidenced by this study based on numerous examples.

A specific dilemma has surfaced whenever each of these principles applies to two different people, and it is not possible to conform in one direction without doing some degree of harm in another. Can one, in order to be realistic, slant response by making concessions regarding autonomy and using pressure, possibly through broadening the scope of legal obligation? There is no simple answer. Answers are more likely found in a approach based on the most scrupulous, the most respectful, and the most comprehensive gathering of information on the consequences for the subject and for the third party. Any attempt to diverge in the slightest from these principles would gradually pave the way to uncontrollable abuse.

In the last analysis, the interest of a third party makes informed consent all the more necessary. Although a large number of situations are fairly simple and there is no antagonism, there are genuine conflicts of interest. Any decision must integrate prior ethical reflection so as to avoid both dogmatism and indifference. Educating society to a better understanding of the meaning of solidarity, is a means of respecting individuals by calling on their sense of responsibility, and informing them on the purpose and altruism of a decision. To consent in the interest of another person is to be both separate and responsible.

[\(c\) 1999, Comité Consultatif National d'Ethique pour les sciences de la vie et de la santé](#)