# Ethical issues arising from the requirement to sign a consent form in palliative care.

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# ETHICAL ISSUES ARISING FROM THE REQUIREMENT TO SIGN A CONSENT FORM IN PALLIATIVE CARE

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**ABSTRACT**

French Healthcare Networks aim to help healthcare workers to take care of patients by improving cooperation, coordination and the continuity of care. When applied to palliative care in the home, they facilitate overall care including medical, social and psychological aspects. French legislation in 2002 required that an information document explaining the functioning of the Network should be given to patients when they enter a Healthcare Network. The signature of this document is required by law. Ethical issues arise from this legislation with regard to the validity of the signature of dying patients. Signature of the consent form by a guardian or trustee, a designated person – the Person of Trust transforms the doctor-patient relationship into a triangular doctor-patient-third party relationship.

## INTRODUCTION

In the French healthcare system, doctors are obliged to inform patients of their state of health, their therapeutic options and the risks of each option, and to obtain consent for treatment. This information is traditionally provided orally and the consent is considered tacit as soon as the patient accepts medical care. Before 2002 written consent was obtained only in cases that were considered particularly sensitive (genetic tests, medically assisted reproduction, abortion, clinical research etc.).

Since enactment of the law concerning French patient's rights (law n°2002-303 of the 4th March 2002 related to patients' rights and quality of healthcare), written consent is also compulsory when patients will be managed by a Healthcare Network (table I).

Table I: Definition of French Healthcare Networks

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| In France, Healthcare Networks first appeared in the 1980s thanks to voluntary efforts of a few healthcare professionals acting independently of regulations and institutional wishes. Regulations concerning these Networks were drawn up in 1996 and 2002.<br>The aim of Healthcare Networks is to improve the care received by patients, by improving coordination, communication and partnerships between healthcare professionals. They improve the continuity of treatment and facilitate management of the multidisciplinary healthcare acts. French Healthcare Networks bring together several healthcare professionals who are more often nurses and doctors, but who may be psychologists, physiotherapists, pharmacists and social workers. The professionals decide to work together in a fixed geographical area, around a particular medical problem, such as asthma, AIDS, elderly people, obesity, diabetes or palliative care. |

Patients must be informed about the type of care planned, that is to say, on the way they will be treated within the Network, and they have to sign the information document about the care the Network provides.

A law published at the end of 2002 concerning Healthcare Networks (decree n°2002-1463 of the 17th December 2002 related to quality criteria, requirements for organisation, functioning and assessment of Healthcare Networks, added to the French public health code as article D6321-3) made it compulsory to furnish written information for any care provided by a Network. Thus, upon entering a Network, the patient receives an information document explaining the services and the organisation of care offered by the structure: the aims of the Network, its mode of operation, and the various actors involved. Furthermore, this document must be signed by the patient, his or her guardian or trustee, a representative of parental authority if the patient is a child or a designated person – the Person of Trust, which can be a family member, a close relative, a friend or the general practitioner. The signature of this information document is the same as an informed consent form, because a patient will not sign the document if he does not agree with the care management provided with the support of the Network.

The aim of this paper is to analyse the ethical issues arising from the requirement to sign a consent form in palliative care and the consequences of this on the doctor-patient relationship.

## ETHICAL CONSIDERATIONS

### For a patient at the end of life, what is the value of signing a consent form

In cases of palliative care, because of the psychological state of the patient, the high level of asthenia or awareness problems due to the illness or the treatment, it is not always possible for the patient to formally sign the consent document.

From a medico-legal point of view, the signature of the document is contestable in such circumstances.[1, 2] Firstly, there is no proof that the person is capable of making an informed decision because of cognitive impairment. Secondly, it does not necessarily indicate that the patient has really understood the information given and therefore the process in which he is engaged. Indeed, signing an information form merely indicates that the information has been received.

The question of the stage at which it is no longer reasonable to try to obtain the signature must be asked. There is no unequivocal answer and each case must be examined individually. If the patient is unconscious or has severely diminished awareness, it seems logical to seek the signature of a third party as specified in the law, the guardian or trustee or, if designated, the Person of Trust.

Whereas until this moment the doctor-patient relationship was a one-to-one relationship based on mutual trust, it now involves three parties and has become a triangular doctor-patient-third person relationship.

**Place of a guardian or trustee in the care relationship**

A guardian or trustee is a person appointed by a magistrate to manage the assets of a person who is not able to do so by himself. The guardian or trustee can be one of the parents of a child, a member of family, or another person, when the patient is an adult suffering from dementia, neurological and psychiatric disease or the after-effects of traumatic injuries. When a patient under guardianship or trusteeship enters palliative care Network, the guardian or trustee must be asked to give consent to the care management provided by the Healthcare Network.

Most often, the guardian or trustee is not a family member, but a member of an association of guardians or trustees. His role is to administer the patient's assets and not to manage his health. As he does not know the medical history of the patient, he is not able to make the best care decisions for the health of the patient.

In cases when a guardian or a trustee has been appointed, a doctor must not dispense with the requirement to obtain the consent of the patient if possible. Indeed, a patient who is unable to administer his assets is sometimes able to make his own decisions about care management.

Even though the signature of patient under guardianship or trusteeship is not legally valid, the effort to obtain oral consent reinforces the relationship of trust between patient and doctor.

**Involvement of a designated person – the Person of Trust**

Since enactment of the law concerning French patient's rights (law n°2002-303 of the 4th March 2002 related to patients' rights and quality of healthcare), healthy or ill patients without dementia or cognitive troubles can designate a person in whom he has trust, called

"Person of Trust" before they are seriously ill and unable to decide for themselves. This person will be designated by the patient himself in a written document, and not by a magistrate as is the case for the guardian or trustee. A patient under guardianship or trusteeship is not allowed to designate a Person of Trust. The patient can designate a family member, a friend, a close relative or his general practitioner as the Person of Trust. The role of the Person of Trust is to advise, help and accompany the patient through out the period of care. If the patient is unable to understand information and consent to the care proposed, this person must be provided with the information, which is a special dispensation allowed for in medical secrecy legislation. The point of view of the Person of Trust may help the doctor to reach a decision with regard to the continuity of care.
But though the Person of Trust can be provided with information, the French law of 2002 did not empower this person with the right to give consent to care in place of the patient. However, the law concerning Healthcare Networks gives more power to the Person of Trust and does allow him to sign the consent form. Thus, the Person of Trust is asked to give consent in place of the patient.

This law involving the Person of Trust in patient care management introduces a concept that we can call ‘representative consent’. How can one be sure that the wishes of the patient will be correctly expressed by his Person of Trust? What will be the standpoint of a doctor coping with a point of view he disagrees with? In palliative care Networks, this situation may arise when the carers want to enter a patient with cognitive impairment into the Network, even though the Person of Trust disagrees with this management solution.

Giving such power to a third person in the management of dying patients can raise ethical dilemmas that have not yet been evaluated. Can the doctor decide to implement a decision

made by a third party, without considering the relationship of trust which links him to his patient? Is it better for him to consider the wishes of the patient's family rather than the Person of Trust, guardian or trustee?

**What place is left for family and close relatives?**

In the law there is no provision that authorises relatives of the patient to sign consent forms or information documents on his behalf. But in practice, management at home cannot be undertaken without the active support of close relatives. Indeed, a patient whose proxies are unable to maintain him at home can not be managed at home with the help of the Network, even if the patient agreed to this management.

Moreover, home care closely involves proxies because it disrupts of the home environment. In addition to the emotional burden of accompanying a dying close relative, the patient and his family may feel that some aspects of the care provided intrude on their private lives. Many health carers will need to go into a home to install a medical device: medical bed or, morphine pump, or adjust the lavatory, etc. Consenting to enter a palliative home care Network is consenting to this intrusion.

The consent of relatives thus adds to the consent of the patient, which is equivalent to family consent. Thus the doctor-patient relationship becomes a family-doctor relationship.[3, 4]

**CONCLUSION**

Though the signature of a consent form is required by law, healthcare professionals must be aware that the relationship with the patient is based on trust and that they must always make decisions for the good of patient and in all honesty.

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