"Death Organized by the Doctor": End-of-Life Decisions in Intensive Care Units

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ABSTRACT

Intensive care and the intensive care techniques in use have considerably changed our attitude towards death and dying –a process that had already been medicalized and professionalized. This study of four intensive care units (ICUs) in France and Britain brings to light the reality of death-related practices and resituates that reality at the core of professional relations and personal experience. Study results strongly suggest that the end-of-life decision is a genuine social construction: far from being purely objective and medical, it is heavily conditioned by context and actors' commitment. The search for professional autonomy and self-regulation has increased the ambivalence of the dying process, already complex because governed by extremely heterogeneous types of logic. This study shows that patient's death in an ICU is more dependant on the organization and culture of the ICU than on patient's own wishes or those of close relatives.

Today in France over 70% of the population dies in the hospital, and nearly half of these hospital deaths occur in intensive care units (ICUs) (Lemaire, 2003). A question immediately arises: How do people die in intensive care units? There are two prevalent types of death. The first is *natural* and results from the ultimate development in a pathological process. The second is *produced* and *constructed*; it results from a decision to withhold or withdraw treatment. This study is focused on the second kind. When intensive care techniques were developed in the 1950s, only their benefits were perceived. But the perverse effects of this medical "prowess" and the complex situations it creates for patients and professionals were quickly realized. Hospital teams are confronted daily with the question of whether or not to implement or pursue therapy for patients with highly uncertain prognoses. The need to find a balance between what medicine can do and moral imperatives confronts doctors with a *choice* concerning what can be done and what is humanly reasonable to decide with regard to the treatment that patients are to be given. In intensive care units, these problems arise with special frequency and are particularly difficult to resolve because of the extremely powerful technical possibilities and the urgency of making a decision. The absence of any public or professional debate on this point has created a void that has allowed different "secret", even illegal, practical solutions to be implemented, thus permitting hospital teams to become almost entirely autonomous and enabling quite varied local end-of-life cultures to develop.

Death and dying in adult intensive care units have not been studied much. Studies have recently been done on decisions to end life in neonatal intensive care (Gisquet, 2004; Paillet, 2007), but in France the social sciences seem to have neglected adult intensive care. It therefore seemed to me worthwhile to study the process by which the decision is made to end life in such units. Who participates? Who decides? On the basis of what criteria, and how are the decisions implemented? I show here how death is practiced by medical actors within virtually self-enclosed, self-regulated territories and local cultures specific to individual units. The way end-of-life decisions are made and how death proceeds vary from one unit to another, allowing for the development of genuinely local end-of-life cultures.

Death in intensive care is a moral issue that is now debated publicly, and sociology's role is to bring to light the social dimension of this ethical problem. Studying the context in which life ends amounts to studying ties between actors and the way they jointly handle normative touchstones that are in many cases not well adapted to practice. To check the hypothesis that the particular unit affects decision-making, four intensive care units were studied –three French units and a fourth in England– to check whether unit specificities were or were not bolstered by national specificities. The point, then, was not to do a comparative study strictly speaking but rather to get a more complete empirical perspective on the problem.

Dying in the hospital: sociological study of practices

End-of-life practices in the hospital framework were first studied in the United States in 1960 by Glaser and Strauss (1965) and Sudnow (1967). But as Castra reminds us, few studies at that time addressed the matter of death in terms of concrete practices: "It is more in terms of individual attitudes toward death that this theme has been apprehended. Forms of contemporary dying are often examined outside of any collective work context." (2003, p. 7). Given that most dying is now done in the hospital under medical supervision, how can we fail to study the way this phenomenon is managed, organized and integrated within hospital organizations?

In *Awareness of Dying* (1965), Strauss and Glaser examined the most recurrent types of interaction between dying persons and hospital staff, together with the strategies used by professionals to handle end-of-life-situations and the impact those strategies have on both professional and lay actors and how the hospital itself is organized. Interaction-related problems often arise at the end of life. What should the dying person be told? Should his upcoming death be hidden from him? What should her relatives be told? How should their presence be managed? There is much in the way of negotiation about what information the patient should receive and how the dying is to occur, the moment of death, the type of death desired (slow, rapid, etc.). For the doctor, negotiation goes together with control. He is careful never to lose control of the situation, and he has to know how to handle uncertainty. The

doctor is the one who determines what policy should be adopted with regard to the dying patient. The patient will of course have a role to play but has only minimal negotiating power. It is above all the doctor who initiates the type of "death-awareness context" [1] that will obtain and defines interaction between the patient and the set of caregivers. Forty years after that study was done, doctors in intensive care units have the same power. It is still the doctor, initially in any case, who decides what information is given to the patient and/or the family. The attitude toward death and the dying person is linked to the particular context and to the age, social status and past experience of all professional and lay actors involved. The attitude to death and the dying person –and the particular death itself– are therefore socially constructed through negotiations, strategies, and games of power and retreat.

In *Passing On*, Sudnow (1967) studied the social organization of hospital dying. According to him, death as a social category varies from one hospital to another. It is the result of a process itself organized as a function of ICU workload. In his study of how death is produced, Sudnow was particularly interested in the way the dying person is treated, his body, his corpse, how the process is handled by the hospital staff and how the staff interacts with the deceased's relatives. He found it to be organized in a highly professional way: "Death is a decisional matter" (Sudnow, 1967, p. 72). The doctor is the real manager of the process; he has a "franchise" on death. The doctor makes the diagnosis and prognosis, programs the moment of death, manages the timing, ensures that no opportunity for scientific research is missed, and, in the United States in particular, considers the costs involved.

The dying person and his death are also matters for judgment. There are "good" and "bad" deaths, more or less deserved deaths, more or less troubling ones. The length of the dying process depends on the moral judgment that has been made. Social origin, social condition and age are fundamental features of how actors in the field regard the dying person. A male drug addict who has attempted suicide is more readily abandoned by the hospital team than an executive, father of a family. Likewise the death of an elderly person in no way disturbs daily ICU work whereas the death of a child upsets the entire unit.

Studies of dying in the hospital emphasize the fundamentally social (and no longer "natural") character of such death. Death and the dying person are the focus of many negotiations and professional and emotional strategies. They are at the center of a great deal of social organization that varies among hospitals and hospital units. Death is the result of a process and of different procedures; it depends on judgments made by the professionals surrounding

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(1) The authors mention four types of context: "closed awareness", where the patient does not know that he is soon to die but the staff does; "suspicion awareness", where the patient suspects he will soon die and tries to check her hypothesis with staff on the defensive; "mutual pretense", where both patient and caregivers act as if there were nothing special in the offing whereas both are aware that the patient will soon die; and "open awareness", where things are said explicitly and all actors are aware of the real situation.

the dying person, particularly doctors. Each intensive care unit develops what I call a unit "culture". The death is thus the result of a genuine process whose "meaning" and moment are constructed by professional teams. The studies also recall the central role of the doctor: death is his "territory"; he decides how it is managed and how it will proceed. Death has therefore been professionalized; it is practiced by hospital actors, and the way it occurs varies by hospital unit's local culture.

Participant observation

The way the social sciences have studied the hospital environment inclines the researcher to stick to the methodological tradition of *in situ* observation, following in the footsteps of sociologists and anthropologists specialized in that world, including Strauss and Glaser (1970), Glaser and Strauss (1965), Hughes (1971) and more recently Peneff (1992, 2000) and Vega (2000). In the study presented here, direct observation of end-of-life practices made it possible to get beyond discourse and penetrate to the core of the as-yet little-known intensive care world. This method allowed for apprehending real work as it is done daily.

For me, "participant" observation meant being continuously present for two months in each of the units studied. [2] This enabled me to observe practices and be present during daily visits (when the team gathers at the bedside of each patient to make diagnostic and therapeutic decisions), at unit ethics discussions, and during relatives' visits and their exchanges with doctors.

The four intensive care units studied are all part of teaching hospitals. The first ICU is in a hospital that I have called Saint Paul's and it has 16 beds. The second, in Saint Vincent's hospital, has only 8 beds. The third, Saint Jean's, is large –24 beds– and well-known, as is the last, in Great Britain, which is part of a hospital I called Saint Luke's and has 22 beds. The observations and analyses for this study concern medical practice from 2000 to 2004. *In situ* observation was substantiated by interviews with professionals (doctors and nurses) and patients' families –a total of 136 interviews, all fully transcribed afterwards.

What is it to die in an intensive care unit? Withholding and withdrawing therapeutic treatment

In intensive care units, a number of techniques and procedures are practiced that help keep seriously ill patients alive. An ICU is defined as a unit for treating patients with acute, reversible disorders of the most important organs

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(2) I was present continuously from Monday to Friday, 8am to 6:30pm, for two months in each unit, for a total of eight months of observation.

(heart, liver, kidneys, lungs) or who are likely to undergo such disorders, a situation suggesting the patient may not live long if treatment is not implemented that requires the use of special techniques, expensive material and 24-hour surveillance by specific, skilled, experienced medical and nursing staff.

Medical decisions to end life in intensive care units produce a conflict between several fundamental ethical principles; *i.e.*, preserving life, sparing the patient pain, respecting patient autonomy, justice (in the sense of allotting available resources), truth, not acting badly, acting well and beneficence. For doctors, the important thing is to avoid both being unreasonably stubborn about keeping a patient alive and making an over-hasty decision to end the patient's life. The ethical questions that intensive care unit physicians have to resolve are of several orders: Do they have a right or duty to stop therapeutic treatment? What types of treatment can be stopped? On the basis of what criteria? For which patients? These decisions extend beyond the unit itself and concern society at large. Nonetheless, it is hard to study them in detail. The researcher inevitably runs up against the ICU team's fear of legal proceedings, and this limits how much is divulged about real-life cases and how much information is exchanged between practitioners in different units (Kentish-Barnes, 2005).

To understand the end-of-life process, it is important to be familiar with the medical circumstances in which doctors are contemplating either withholding [3] or withdrawing [4] active treatment (Lemaire, 2003).

The patients concerned are those for whom the prognosis is grim and who are only being kept alive by means of intensive care machines and techniques. For these patients, witholding and withdrawal usually only permit or accelerate ineluctable death. There is another situation, however, where what is at issue is not so much the imminence of death but the quality of the patient's life if he survives. In this case, the medical team does not fear the patient's death so much as her survival in conditions deemed unacceptable, such as being in a vegetative state, definitively dependent on various prostheses, mutilated, having to endure slow, painful treatments, etc. Only exceptionally can a conscious patient express the desire to die and ask for the machines and techniques that are keeping him alive to be turned off. This may happen with a patient suffering from chronic respiratory failure or in the last stage of cancer. Brain death remains a problematic case: it is important not to confuse the

(3) Witholding active treatment means maintaining treatment already under way but not escalating treatment if a new kind of organ failure occurs. A decision to limit therapy may involve maintaining artificial ventilation if it is already under way, but no heart massage will be done in case of cardiac arrest, and there will be no hemodialysis in case of anuria.
(4) Withdrawing active treatment means taking the patient off life-support systems such as mechanical ventilation (a technique that consists of helping the patient breathe by means of a tube inserted in the respiratory paths), hemodialysis or catecholamine drip (a kind of medicine that acts on the heart and/or blood vessels; *e.g.*, adrenalin, noradrenalin and dobutamine). Treatments such as hydration, hygienic care, sedation and analgesics are continued. Use of a lethal injection, called active euthanasia, designates the fact of deliberately inducing death; this is illegal in France.

above-mentioned conditions for stopping treatment with turning off life-support machines in the case of brain death. Brain-dead patients are legally declared dead, and this enables medical teams to ask families if organ donation is possible and to proceed if agreement is obtained (Ad Hoc Committee of Harvard Medical School, 1968).

Lastly, the legal context is fundamental because it represents the general framework in which doctors engage in their practices. In France, medical law does not exist as an independent discipline. The rules derive from civil, criminal and administrative law –all the different law disciplines. French law only recognized the concept of withholding or withdrawing intensive care treatment in April 2005. Until that date, if legal proceedings against a doctor or team were undertaken, magistrates generally choose the accusation of homicide, at best unintentional homicide. Active euthanasia is still considered murder, as indicated by the French penal code. [5] Intensive care medical teams have long had to make decisions situated at the margins of legal behavior and susceptible to ambiguous interpretation if divulged. The 2005 law was aimed to protect both the doctor making decisions to end life and patients' rights insofar as it encourages patient's and/or patient's family's participation in the decision-making process.

Producing death in intensive care units

Death in intensive care units is constructed and organized within a collective work context. In direct contrast to palliative care (Castra, 2003), death in the ICU does not correspond to the ideal of a "good death". In ICUs death is omnipresent (25% of deaths occur in such units) but does not correspond to some given meaning common to all. It occurs daily and does not destabilize work organization; it is nonetheless "violent" and exhausts all actors involved, both professionals and laypersons. Death represents failure for professionals who have been fighting to save their patient's life. This means that it can be hidden and "practiced" opaquely. Death is a problem for the medical profession but also for the institution itself in the sense that that institution can only exist if its members can justify their role. Given that health professionals' primary function is to save patients' lives, they find it a complex task to justify producing death.

Once this question has been resituated in its context it becomes central. As indicated above, 70% of the population in France dies in the hospital today, and almost half of those deaths occur in intensive care units. We are therefore justified in inquiring into the role of intensive care physicians: Have they become regulators and producers of death in the hospital, and even within

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(5) Article 221-1 of the *Code Pénal* states, "The fact of willfully inducing another's death is murder", Article 221-3: "Murder committed with premeditation is assassination". The French medical code of ethics is just as clear: Article 28, § 2 stipulates "A doctor does not have the right to induce death deliberately".

society at large? Is this type of death, so remote from our current ideologies, suitable for citizens? Does *produced, technical* death meet collective wishes and expectations? With the development of alternatives to traditional hospitalization (home hospitalization, outpatient care), the hospital is being transformed into a treatment-giving institution that handles only patients with the most severe disorders. It is reasonable to assume that the relative size and weight of intensive care units within hospitals will grow. The proportional increase in unit size, combined with the fact that ICUs now figure on or near the forefront of death statistics, may affect how often medical staff in this sector are called upon to make life-ending decisions. There is a real likelihood that these units, originally created to "bring people back to life", will take on an additional mission: "producing death" in conditions acceptable to all. This mission, which has long been merely one aspect of intensive care physicians' activity, is today becoming a central practice at the very core of how their work is defined.

Four intensive care units, four specific end-of-life cultures

Each intensive care unit creates its own end-of-life culture, which depends on the personalities of the doctors in charge of the unit, the unit's professional atmosphere, the very meaning of intensive care, the unit's technical, medical, and ethical priorities, and its attitudes toward norms and the law. Because the four units studied are determined to maintain their autonomy and remain self-regulating, they all seek to keep patients' families from partaking in the end-of-life decision-making process –though this often suits the families quite well.

In the Saint Paul unit, the decision to end life has been thoroughly medicalized and it is made within an extremely tense professional and relational atmosphere. Here the number of actors implicated in making the decision is kept to a minimum, and this also keeps the number of issues discussed to a minimum. Decisions are made at patient's bedside on the morning visits (the discussions do go on for a few days, of course). Contrary to the other units studied, the idea of reflecting deeply on the ethical issues of ending life is not part of the conceptual apparatus of this unit's medical team. Its primary concerns are professional. Because doctors dominate and the different types of personnel do not meet with each other, there is no collective commitment on the part of the team at the moment that life-ending decisions are made; this means there is no shared, consistent philosophy particular to the unit. For many of the actors here, decisions to end life make no sense. The culture and organization of the Saint Paul ICU are characterized by permanent tension between medical and nursing teams. These conflictual relations have major effects on how the end-of-life decision-making process develops (it is often quite fragmented) and how patients die. Nurses do not partake in the decision-making process. The decisions are thus implemented by doctors only, doctors wary of the autonomy that nurses could acquire in the absence of any team

consensus. Both the decision-making process and the dying process are quick in this unit and involve practices that reflect strong autonomy with regard to recommendations and laws. Saint Paul doctors' wish to keep discussions and the decision-making process highly informal, ensure their professional autonomy, justify self-regulation and make it possible to keep nurses and families at an even further distance from what is happening.

At Saint Vincent's, the opposite holds. Professional group relations are at the heart of the decision-making process and constitute a criterion for whether or not that process is proceeding smoothly. Here we see what can be described as an "ethicization" of the decision-making process, involving deeper thinking about the meaning of the care and treatment to be given, the meaning of death, and the experience of the various actors involved. This collective aspect lengthens the decision-making process and thus delays the moment of the patient's death. Unit organization affects how patients' deaths are organized: "No deaths on Tuesday", say the team members, because that is the day the team meets, the day ethics-related decisions are made. The families should not be able to make any direct connection between the staff meeting and their relative's death. Lastly, the experience and itinerary of the practitioner in charge of the unit affect how the decision is made as well as how it is acted upon. Injecting a sedative that will induce death before extubation is in fact an illegal technique but it was long practiced for the "comfort" it affords the practitioner (quick, relatively easy death). The doctor who recently took charge of the Saint Vincent ICU prefers to do things differently; he prefers stopping active treatment, including assisted ventilation when possible (this is recommended by scientific society experts). Paradoxically, hospital professionals may find this method difficult to implement because of the reactions it provokes in the dying person (patient gasps, turns blue, gives the impression of struggling for air). This doctor, trained first as a lung specialist, [6] has the expert knowledge required for withdrawing this life-support system and has taught his team how to extubate [7] gently in order to make the death less violent. At the time of my study, and even though this method has been recommended, it was not very widespread in France, where the general preference is for turning the respirator down or off without taking out the tube; this is combined with heavy sedation. Since each doctor has a different itinerary, each unit has a different culture when it comes to ending life. In order to protect themselves against all misinterpretation of the procedures used, particularly since ratification of a law in France facilitating patients' or their surrogates' access to medical files, doctors in most units do not explicitly note the end-of-life decision in the patient's file. This attitude clearly facilitates autonomy in the realm of practices and decision implementation.

(6) Intensive care in France is an additional medical specialization. Before becoming an intensive care physician, a student has to obtain certification as an anesthesiologist, cardiologist or lung specialist. S/He then pursues studies to obtain a degree in the complementary specialization of intensive care, which permits him/her to practice in an ICU.

(7) Extubate: take out the tube linking the patient's respiratory paths to the respirator.

The Saint Jean intensive care unit is characterized by a "top-down" approach, strongly hierarchical organization and a multi-step decision-making process (several days of discussion at the morning staff meeting and during the bedside visit, followed by a meeting to make the decision). The process here is even more fully "ethicized" than at Saint Vincent's in that not only social but also economic criteria are taken into account (this is the only unit studied that mentioned the cost of futile intensive care hospitalization), as well as management-type criteria (the policy in this unit is to "keep a good bed turnover"). Moreover, there is a person working there who is in a position to change attitudes: the unit can call upon a psychiatrist specialized in end-of-life issues, and this allows for fuller and deeper reflection and the development of a unit culture founded on the theoretical idea of reducing the violence of the death. The near-military type of organization in this unit goes together with an approach in terms of efficiency that affects how decisions are acted on. When I was there, this unit was characterized by what is called an "active" approach, whereas elsewhere the process is likely to be slower. Instead of extubating certain types of patients and letting them die, doctors in this unit sometimes prefer to inject strong doses of sedatives and even potassium, depending on the type of patient (though potassium is much less likely to be used), to bring about patient death before extubation. This is strictly prohibited by law, but the act is deemed less hypocritical and more manageable for the medical team. Doctors justify it by stating that it shortens the family's painful wait. This attitude toward technique enables those in charge to feel they are in control and reduces zones of uncertainty: through this act, the doctor knows exactly what the patient's reactions will be, whereas with "slower" techniques, one can never predict how the patient –his body, at least– will react.

The unit at Saint Luke's in Britain is characterized by a very long decision-making process. Discussions on ending life often begin at the morning staff meeting and continue through the medical round; the decision is often made at a specific meeting called to that end. Discussions last several days, even weeks. Many unit features work to slow the decision-making process; namely doctor rotation (the consultant in charge of the unit changes every week) and fear of legal proceedings. Here we find a kind of legalistic approach to the decision-making process in that what is "good" is what is "legal". There are three types of decisions: explicit decisions, implicit decisions, and, often, non-decisions, which are nonetheless a type of decision in that all the actors are aware that the patient's condition has worsened in the time elapsed. Given the fear of legal proceedings and the strong presence of relatives, life-ending techniques here are more transparent than in the three French units. Attitudes toward those techniques are in fact determined by the respectful attitude toward the law –a priority here. Doctors refuse to take any risks, even if doing so means there are no beds available for other patients. Indeed, this attitude raises a problem of consistency and may actually cause suffering to staff and patients' relatives. Doctors here actually seem to be avoiding having control

over the situation, since such control would be too dangerous over the long term. [8] The rule tends to be to let things continue as they are, and this considerably lengthens the process. But this attitude also allows for total transparency with regard to relatives and it seems to preclude feelings of moral guilt –which may be strongly present elsewhere.

Saint Paul's life-ending culture, then, is characterized by doctors' autonomy in making and enacting life-ending decisions and the absence of any collective spirit. Autonomy within the unit goes together with autonomy with regard to the outside: doctors medicalize the decision-making process and disregard recommendations and norms that do not suit them. Here the dying process is quick and secretive, much goes unsaid. At Saint Vincent's, the culture is founded on a collective spirit. Nurses participate in the discussions and help enact the decisions made. Given doctors' possible doubts and the fact that a great many actors are involved, there is a concern in this unit for respecting the law and rights (though not systematically), and this makes the decision-making and dying processes much longer than in other units. The culture at the Saint Jean unit is characterized, on the contrary, by decisions that involve a great deal of discussion but are quickly reached, and by faster modes of dying. Here there can be no doubt: doctors try to control the patient and his death, regardless of legal constraints, and they reserve for themselves the responsibility of enacting decisions to end life. Lastly, the culture in the Saint Luke unit is characterized by a very long, collective process –the point may even be to avoid death. This is due to poor unit organization and staff rotation, also to fear of possible lawsuits. Contrary to the other three units, there is great transparency at Saint Luke's, and despite the fact that the decisions made are strictly medical, the responsibility for enacting them falls to nurses.

Decisions to end life are made in an ambivalent context

Decisions to limit or stop therapeutic treatment are made in a highly complex situation. The medical context is of course central, but teams also have to take account of prevailing work relations in the unit and the legal context. Decisions are likely to be based on the nature and development of a chronic disease, the failure of a specific organ (namely the brain), the number and severity of other organ failures, patient's response to treatment, practitioner's prognosis and assessment of the estimated quality of patient's future life. Other, less "medical" criteria are also taken into account: patient's stated

(8) I did not observe practices in other intensive care units in Britain, so it is hard to determine objectively whether this attitude is specific to the Saint Luke's unit or is widespread in the country. Interview material alone seems to confirm the first idea. The fact that the decision-making process is slow and that the team "flees" patient death for fear of incurring legal proceedings seem characteristic of the local culture at Saint Luke's. Elsewhere in Britain, teams act more quickly and calmly, and this supports the hypothesis that the particular unit is decisive in defining end-of-life culture.

wishes (living will), patient's age, relatives' wishes and/or attitude (these are not necessarily explicitly expressed), patient's social context and whether or not she can be cared for if she should need continuous lifelong treatment (a homeless person without any family who needs a tracheotomy may not receive that treatment because he has no network or resources for dealing with the health problem after leaving the hospital). The economic dimension of patient care is mentioned but does not constitute a decisional criterion. In this sense, if it is difficult to reach consensus on the end of life issue, the team will choose to pursue treatment temporarily despite high costs. [9]

The different types of logic in operation in these different "worlds" are not always congruent with each other, and doctors have to balance extremely dissimilar demands and constraints. Actors' "responsibility" is coming further and further to the forefront, and it is "always the meaning attributed to the act that determines how it is evaluated" (Touraine and Khosrokhavar, 2000). At the center of the professional actors' activity (that of doctors and nurses) is the ability to act not according to duties or texts but as "moral" beings focused on "the other" (the patient and his family) and themselves. In practice, determining how to combine a universal and a particular dimension, an ethics of responsibility and an ethics of conviction (Weber, 1959), is a problem encountered daily.

There are many different kinds of ambivalence in intensive care units: ethical ambivalence, as we have seen; ambivalence related to death itself, but also to the patient and his family. Death is indeed the outcome of a considerable number of ambiguities that society is careful to pointing out; administered death and natural death are differentiated in society, whereas in ICUs the borderline is becoming increasingly blurred. Violent death and natural death are also distinguished from each other, whereas in intensive care the dividing line is much less explicit due to the treatment context itself. Lastly, death itself is ambivalent. The difference between "real" death and technically-induced death is what allows for organ donation, but it also makes managing death difficult for relatives: "The more technicized death is, the more difficult it is to distinguish it from life." (Bayertz, 1992). Moreover, death –that painful event feared by all– should here take on the opposite meaning because it should represent the patient's best interest, the "right decision", the one that will be agreed upon by the greatest number.

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(9) Several studies have shown that the highest costs correspond to patients who do not survive in intensive care. Most of them become dependent on life-support techniques and use up a major proportion of available resources before dying. 60% of American intensive care professionals think that the cost-benefit ratio does not count for much in the decision to stop treatment (Society of Critical Care Medicine Ethics Committee, 1992). In France, studies show that intensive care physicians are conscious of the cost of their techniques, but that this factor does not intervene in end-of-life decisions. Economic cost is the criteria least likely to be used by French intensive care physicians (used in 3 to 8% of cases) (Pochard, Zittoun and Hervé, 1999).

A great deal of ambivalence also crystallizes around the patient because he is both absent and present: absent in that he is unconscious and under sedation –therefore absent as an actor– yet present because his body is there –that body can even become an encumbrance. During hospitalization, the seriousness of the patient's condition may lead to him being dismissed as a Person, but that Person returns forcefully at the moment of death: she is no longer the "patient being treated" but rather "a person at the end of life" and thus raises problems that the actors had tried to conceal up to that point.

The patient's family is also the focus of this double game; its place is ambiguous. The patient's family seeks a highly "Parsonian" relationship, and therefore often flees the responsibility of making decisions. Family participation in the end-of-life decision is generally implicit and may actually amount to a perverse effect: family members' words weigh on the decision without their necessarily being aware of it. The family is an actor in the decision-making process, but an actor in spite of itself, a "passive" rather than "active" actor.

It is within this decidedly ambiguous medical and relational context that intensive care teams make end-of-life decisions and implement them (surprisingly, this aspect is not often mentioned in medical publications, whereas it may actually prove most problematic for the doctor). The patient's death involves professionals and requires them to make moral, social and legal choices whose effects on their own experience they do not really control.

Who makes the decision?

Doctors

Regardless of the unit's particular culture, doctors are the main decision-makers. Their sovereignty in this matter, in both French and English hospitals, is a crucial point. Doctor's autonomy as described by Friedson is still a strong value; it even amounts to an action principle. In the end-of-life context, the doctor plays a central role as "moral authority". His responsibility is constantly being forefronted; it makes him the point around which end-of-life decisions pivot and are organized. This responsibility in turn strongly affects doctors: "[...] we're the doctors; the responsibility must remain medical. We're the ones who choose what treatment we give, what technique is to be used. The decisions are ours –all of them [...]" (senior registrar, Saint Paul's). Another doctor expresses the same idea less defensively: "I think it's our role. It's our role, but not necessarily one doctor's –several doctors'. We signed up for that role and, you know, we were talking a little while ago about staff meetings, but the [end-of-life] decision is a medical decision. [...] It's not in terms of medical training, it's our experience... and yes, I think it's our role [to make these decisions]." (senior registrar, Saint Vincent's). Decision-making responsibility is therefore central to the definition of the medical profession and the intensive care physician's identity. It refers to values

strongly anchored in the profession. As Parsons (1955) showed so well, the doctor is traditionally responsible for the patient's well-being. In this context, he is expected to use appropriate skills and techniques –he has control over the situation. He is expected to belong to a world of rational, universal norms and values, norms and values that long enabled the hospital institution to remain "a world apart". Each member keeps to his role, that of doctor or patient, and one characteristic of the patient's role is to be exempt from all responsibility. Friedson (1984) showed how the concept of "responsibility" fully defines the medical profession. For him, this term refers primarily to an archetypal feature of medical practice: a doctor holds the patient's fate in his hands; the patient's life or death depends on the doctor. Responsibility is understood as the practitioner's essential, decisive act, and Friedson explains that a doctor is most a doctor when exercising this responsibility. This under-standing of responsibility, shared as it is by doctors and patients, allows for a certain degree of autonomy for doctors and gives them near-exclusive control of the work to be done.

Responsibility, a fundamental characteristic of nearly all medical practice, is emphasized and intensified in intensive care because the decisions bear directly on the patient's life or death. Responsibility comes to the fore when the medical staff is faced with "difficult cases" where they have to innovate while maintaining the consistency of the decision-making process: death is decided and produced. This paradoxical situation is related to medical pro-gress. The scientific and medical culture we live in has deeply disturbed both our attitudes and doctors' practice. Doctors often find themselves entirely alone with the difficulty. They are asked to manage both medical progress and all the disturbances that such progress generates. Society offers little in the way of an answer to the concrete problems, and doctors therefore have enor-mous responsibility in these difficult situations. It is up to them to invent norms and judgment, to make "the" decision. The following example, observed at Saint Luke's hospital, provides a fuller account of this situation. An 81-year-old patient was admitted to intensive care for a severe lung infec-tion. His condition worsened during his stay; he became muddled, had to be intubated, lost consciousness. The prognosis after nine days in the ICU was not good, and it was decided not to escalate therapy: there was to be no new treatment. For three days the patient remained in a comatose state; during this time no other specific decision was made (see the section above on the parti-cular culture at Saint Luke's). Gradually the idea developed that he was in an end-of-life situation. On the twelfth day of hospitalization, a Monday, a senior physician took me aside during the visit and asked me: "And you, what do you think regarding the human side of things? Do you think he should die?" Sponta-neously, because this was an informal discussion, I replied, "Yes –for his sake, poor thing." The doctor then brought me to the patient's bedside. He said, "You shall be my witness." He lowered to a minimum the amount of oxygen the patient was receiving. The patient died before our eyes in a few minutes. As he left the now dead patient's bedside, the doctor said to me, "Too much torture... It was for our own consciences that we didn't do it

earlier. I should have been firmer with myself, I should have done it last Friday. But the problem is that the patient died very quickly and I feel as if I've just killed him." The active move goes together with a moral difficulty that everyone in the unit tries to elude. Here the researcher, a representative of the non-medical outside world, was instrumentalized to allow the doctor to act according to his principles but not in solitude. Doctors' responsibility is therefore ethical and linked to a context that is both social (lack of touchstones, taboos, etc.) and "local" (the intensive care unit as a specific place). In thus engaging his responsibility, the doctor has to be willing to use increasingly heterogeneous types of logic (Dubet, 1994), and this requires him to think hard about his professional, social and individual role. "One decides in accordance with one's conscience. It's a decision that involves the responsibility of the senior physician and of all those who partake in that decision." (doctor and medical professor, Saint Jean's). All four intensive care units abide by the rule that it is first and foremost doctors who make these decisions, regardless of the possible effects on their professional and personal experience.

Nurses

Nurses are often at the center of debates among professionals. Nurses have direct and prolonged contact with patients and their relatives but do not actively invest in the end-of-life decision-making process. While end of life is an ethical problem subject to discussion, nursing personnel are actually willing to leave the responsibility for it to doctors. "Their arguments [doctors'] seem perfectly valid to me, and I think it's pretty courageous to take on that responsibility. [...] I don't think I have the knowledge required to make that decision, actually, so I would be really troubled if someone said to me, 'We won't do it until we get your ok'. That they should wait for my 'no' so as not to do it is one thing, but that they're waiting for my go-ahead... I don't have the knowledge they do, I don't have a doctor's experience, I don't have the skills –it's not up to me to do it." (nurse, 33, Saint Jean's). The nurse's need for recognition is stronger than her real participation in the end-of-life decision. The more recognition nurses feel they get for their work, the less likely they are to want to have some responsibility for making the decision. This is the case in the Saint Vincent, Saint Jean and Saint Luke units. It is only at Saint Paul's that nurses demand to actively participate in the end-of-life decision-making process, because the nursing staff there experiences identity-related tensions and strong professional frustration. The important thing is to be recognized not as a real participant in the decision-making process but as a potential one.

When it comes to implementing the decisions made, the medical and nursing staff are dependent on the unit culture and the type of death the doctor has chosen to produce. In units that prefer gradual reduction of treatment (a legal process), as at Saint Luke's, the dying process is the nurse's responsibility. In units where death is faster and more "violent" (and processes may be illegal), as in Saint Jean's and Saint Paul's, doctors are fully responsible for

the patient's death. In the Saint Vincent unit, where the collective comes first, doctors enact decisions together with nurses. The important point is that it is not usually the death itself and the act of inducing it that are problematic (the nurses are willing to participate) but everything surrounding the death; *i.e.,* the decision-making process itself and dealing with the patient's relatives. For some doctors patient's death is "easier" than having to announce it to the family.

Relatives

Sociological thinking about the role of patients' families in intensive care units emphasizes the autonomy of the medical team and the strength of medical power (Gisquet, 2004). In her studies on end-of-life decisions in neonatal intensive care units, Paillet (1997, 2007) emphasizes the "protected" place reserved for parents: they are kept at a distance from the decision-making process, even from discussions and information. The author points out the inconsistency between this state of affairs and the consent norm that prevails in medical practice today, stressing that ethics are here totally medicalized. In neonatal and adult intensive care, three arguments are cited to justify leaving the family out: the family needs to be protected; it has no competence in these matters; and the patient's interests have to be kept independent of the family. These three arguments are used to legitimate the "medical paternalism" that it is considered good form to denounce these days. In the four intensive care units studied, patients' relatives are not recognized as participants in end-of-life decisions, including at Saint Luke's, where there is the fear that families will retaliate with legal measures. There is total transparency in that unit, but the team follows its own perception of the case and makes its own decisions, leaving little maneuvering room to patients' relatives. In reality, the medical teams induce the families to participate in spite of themselves: as mentioned, words uttered by relatives may be used by professionals to justify, argue in favor of, or delay a decision, without the relatives being aware of this. They thus play a role in the decision-making process, a role that suits the professionals, but that they are not necessarily aware of playing. This point must be qualified, however: surprisingly, very few of the families I met with wished to participate explicitly and openly in decisions concerning the patient. While the family thinks it has a duty to inform the medical team of the patient's wishes, it usually does not perceive itself as having a role in decision-making. Discussions and decisions belong to the medical sphere here. The separation between worlds, the Parsonian "us/them" dichotomy, is central: on the one hand, the doctors, who have the knowledge and skills; on the other, the laypeople, ignorant of medical matters and too emotionally implicated. Curiously, the relatives use the same arguments as the professionals to exclude themselves from the decision-making process. Most families cannot imagine participating in the end-of-life decision process. "I would not want to participate, because I would not really know what I was participating in", the wife of a 55-year-old Saint Luke's patient told me.

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"They know what they're doing. I don't understand everything. All that matters to me is that they make the best decisions for my husband. I trust them."

Seeking autonomy despite a context of uncertainty

If doctors continue to be the primary decision-makers, this is because they are the masters of this particular territory. As mentioned, the end-of-life culture specific to each unit reflects a high degree of autonomy, and this characteristic is likely to raise problems at times. The "decision" no doubt constitutes the central issue for all ethics-related thinking on medical practice. To take up an idea of Paul Ricoeur's (1990), moral obligation, wisdom and just decisions are at the heart of the so-called "ethical" approach. End-of-life decisions are at the core of this approach. They involve actors' moral sensibility, their sense of what is right and just. They directly engage their responsibility, a responsibility linked to their role and their status as "persons". More than any other doctor, the intensive care physician is confronted daily with death, and death engages his responsibility in the sense that it is usually the result of a decision he makes –and hardly a minor one! It is important to recall that most treatments in intensive care units are life-supporting. Once implemented, a decision not to use or to stop using a treatment or technique can induce death in a few minutes or hours.

While this last phase seems to represent a clear-cut alternative –life/death– in daily practice things are usually much more complicated. "I would go so far as to say that truly difficult moral problems do not involve choosing between Good and Evil. The most difficult cases are those where one has to choose between grey and grey." (Ricoeur, quoted in Hervé, 1997, p. 29). Ricoeur is quick to recall that some doctors are more likely than others to have to deal with what legal specialists call "hard cases", those in which it is not clear what rules should apply. It is precisely in such a context that "both norm and judgment have to be invented. These are real problems" (*ibid.*). Intensive care physicians regularly have to deal with such "hard cases", cases that lend themselves to debate and controversy and generate uncertainty and tension. Given that a doctor has to create norms and ways of shaping judgment, we can say he is twice responsible: his status and role as doctor is on the line, but he is also legally responsible. We can even say that his responsibility is engaged threefold because his very person is implicated: it would be misguided to believe there is anything like total objectivity or that no personal judgment is being made.

Uncertainty has much to do with the idea of prognosis. It is not always easy to "predict" the quality of a patient's future life, how handicapped he will be or the loss of mental capacity he will suffer. An extremely important role is attributed to prognosis, and this point is worth reflecting on. In a book on medical prognosis, the American sociologist Christakis (1999) shows how frequently errors are made. In his study of 365 doctors called upon to give a

prognosis for 504 patients, only 20% of the predictions proved correct (1999, p. 67). Each different medical specialty has its own prognosis culture. Doctors such as cancerologists who deal with chronic diseases and know their patients well are likely to be extremely optimistic. On the contrary, doctors confronted with emergencies and acute illnesses tend to be pessimistic. In 1985, a study by Dr Detsky (cited in Christakis, 1999) forefronted this culture of pessimism in intensive care units. Researchers collected survival estimates for 1,831 patients who had undergone massive intensive care treatment. When real survival rates were compared to the doctors' estimates, doctors proved particularly pessimistic: 63% of patients whom doctors had given only a 21 to 40% chance of surviving did survive.

Doctors may be afraid of making a prognosis, but doing so also enables them to reaffirm their authority and makes them feel they are in control, a feeling that may be missing, especially when it comes to end-of-life issues. Putting forward a prognosis makes it easier to decide to withhold or withdraw therapeutic treatment. Christakis shows that pessimism becomes a ritual in intensive care and serves to normalize expected failure –that is, the patient's death. Pessimism thus becomes a tool for making and acting on end-of-life decisions. A grim prognosis enables the doctor to perceive the patient's death as once again a fact of nature rather than a direct result of his intervention. Still, the risk of error is very real. Each doctor, or rather each unit, has its "mistake" anecdote, and they do not hesitate to mention it at moments of doubt. Christakis draws a parallel between these "stories" and the notion of folklore in the sense that the stories are steeped in notions of justice, irony and morality. They touch on taboo transgression –here the taboo of causing death. I was told such stories in each unit studied (often several times by different actors) to make me aware of the risk involved in predicting and making decisions. The following is one such story, related respectively by a medical professor, a registrar, a nurse and the unit's physiotherapist:

> The story of Peggy
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> In 1991, a 15-year-old patient named Peggy was hospitalized for *purpura fulminans*, the most serious form of meningitis. The medical team quickly realized that if she survived she would suffer heavy side-effects. Her case was very difficult, involving relapses, complications, amputation, a great deal of uncertainty on many points. After she had been in the hospital a month, some doctors started arguing that treatment should be stopped, particularly on the basis of estimated future quality of life. Long debates were held, but since proponents of withdrawing active treatment were in the minority, therapy was continued. The patient left the unit a month later with serious side-effects of the disease: she was deaf, her kidneys had definitively failed, and she had had to have the extremities of her feet amputated. She remained bedridden for several years –years in which she also obtained a high school degree and began legal studies. Today she is a jurist. The doctor responsible for this patient during her stay in the intensive care unit was the one most strongly in favor of withdrawing treatment. This experience affected him deeply, and for years he kept in contact with the young woman. What shook him most was what Peggy said to him one day when he was having lunch with her in a restaurant: "Can you imagine", she said with humor, "if the others had listened to you, we would not be here eating together –I would be dead!" This story is told to all doctors and nurses new to the unit. It is related with humor, but this sometimes conceals a certain unease. It is of course also related with the aim of teaching doctors who will be called upon to make such decisions to think carefully before doing so.

This example shows to what degree doctors' subjectivity and judgment come into play in decision-making. Here doctors defined what seemed to them an acceptable or unacceptable quality of life for the young woman. The fear of making the same type of mistake prevents certain doctors from fully trusting their own and colleagues' prognoses. They become wary, and actors may therefore prefer long, rather then rapid, end-of-life processes, and they may prefer not to have total control over the dying process. How uncertainty is handled varies from unit to unit, giving rise to different ways of managing end-of-life decision-making. In the Saint Vincent unit, for example, discomfort with contextual uncertainty may considerably lengthen the decision-making process and thus delay the patient's death. This discomfort may also increase the number of involved actors who opt for a fairly slow end-of-life process, to avoid regrets and to give the patient "another chance".

Rejecting intervention from the outside

The end-of-life context in intensive care units may be characterized –though not always– as a multitude of uncertainties (quality of life, patient's wishes, sincerity of relatives' emotions, [10] etc.), uncertainties that the doctor has to assess in making a prognosis and a decision. This will have a strong impact on how involved the doctor gets –his professional and personal commitment. Despite the difficulties encountered, doctors generally refuse to accept any participation or help from outside actors. Intensive care doctors like to remain somewhat isolated and independent, and this in turn strengthens ties within the unit (some even speak of passion-type professional relationships). As one doctor put it: "We are in a system that runs on mutual trust." Acquaintance networks, the fact of sharing the same values, and the issue of responsibility make ICU workers mistrust and sometimes reject the very idea of intervention from outsiders –*e.g.*, members of an ethics committee– when the moment comes to decide to withhold or withdraw therapy. This feeling of mistrust often follows from the system of self-regulation, a "world apart", the extremely strong trust obtaining among colleagues. This was clearly expressed by one doctor I spoke to: "Someone from the outside, ok, but it's never very easy. It means he has to have real ability recognized by the outside. [...] Those people have to have an intensive care culture. [...] And they really have to be people we're used to working with. If we take someone from the outside, the staff have to have confidence in him." (consultant, Saint Jean's). Certain fears resurface: fear of losing authority, fear of bureaucratization and slowed procedures, fear that the informal culture founded on daily shared working life will come to an end. "What bothers me, in fact, is that bringing in someone like that immediately means formalizing things, and I'm sure that will block debate –that's what bothers me about it. If

(10) Medical teams may find that certain families' attitude and comments do not seem entirely honest. They may suspect that there are issues of family conflict, expected inheritance, etc.

you told me that the person was going to be there every day, that he'll always be there in any case, that's different." (senior registrar, Saint Vincent's). The informal aspect of decision-making processes in intensive care seems of central importance to all actors.

Doctors are often wary of experts in medical ethics. They criticize them for their lack of practical experience, their theoretical bent, their tendency to "lecture". Some of this criticism is quite bitter: "Ethics is intellectual mastur-bation" (medical professor, Saint Jean's). Institutionalized, formal ethics thinking seems to them too remote from practice, and intensive care doctors prefer to stick to themselves when it comes to making decisions. They believe that decisions reached that way will be better, even if it gets them involved in a professionally and personally complex process. Two notions appear impor-tant in arguments against intervention from ethics committees: the notion of knowledge, which should be *shared* and *used* by all discussion participants; and the notion of the person. The idea in the second notion is that any indi-vidual who partakes in the discussion should have been socialized by a process of learning and acquiring practical and intellectual skills that make him or her a subject capable of intervening effectively –a legitimate subject. This recalls some of the conditions that Habermas (1992) put forward for "communicative action".

Several features may be mentioned: the desire to have exclusive control over the work they have to do; the fact that their professional identity may be called into question; and the existence of what is in fact a conflict of interests, the idea being that it is in the patient's best interests for doctors to act without intervention from an ethics committee (despite some uncertainty): medical autonomy will ensure better care of the patient.

The idea of having treatment givers specialized in palliative care intervene in intensive care is just as controversial. Intensive care and palliative care are often presented as two worlds that cannot be made to coexist. Collaboration between the two types of teams is usually rejected because of the desire for exclusive control over the field of intensive care. Autonomy is the implicit refrain in all these remarks. For Pouchelle (2003), ICUs are special action fields whose purpose is to stage the myth on which the teaching hospital edifice is founded; namely, the possibility of healing the body without really attending to the person's particular history or psychology –what Pouchelle calls "*désanimation*." (11) Scientific rationality is the imperative and must leave no room for end-of-life "accompaniment" and palliative care. Moreover, bringing in end-of-life specialists would amount to intensivists' admitting their own weaknesses and letting themselves be dominated by uncertainty –a difficult thing in intensive care culture, which is founded on endurance (Dejours, 1999), daring and control.

(11) [NB: the French term for intensive care unit is *service de réanimation* –Trans.]

Up against the difficulties and uncertainty of some end-of-life contexts, intensive care doctors choose internal control and refuse to admit of doubt, as this would be sign of weakness. The need to present an opinion, a prognosis, remains the responsibility of intensivists alone and involves them fully in both professional and human terms. Each unit is headed by individuals with specific personalities, experiences and values. These "heads" set the tone, dictate how end-of-life decisions are made and implemented. Each unit has its own way of handling uncertainty. Here this means four distinct "cultures" for surmounting the situation of uncertainty. Saint Paul's is characterized by *denial* of uncertainty –a way of avoiding conflicts; Saint Vincent's by fully *integrating* uncertainty, leading to a slow decision-making process; Saint Jean's by an emphasis on *efficiency*: "There is uncertainty, but we have to decide and act consistently with that decision" –here the decision-making process is faster than elsewhere; and Saint Luke's by the *fear* of uncertainty, which brings with it a desire to be relieved of problematic cases, though the real reason for fleeing the problem is not explicitly admitted. The territory of intensive care is hedged with borders that actors try to protect as fully as possible, particularly today, as external control over professional practices is being strengthened.

The autonomy and self-regulation characteristic of intensive care units directly affects how patients die, and the decision-making process characteristically excludes external third parties. Intensive care teams have appropriated the matter of producing death. Their first concern is to make death as predictable as possible so as to better control it; also to minimize the "violence" of the death for the medical team. But different teams assess such "violence" differently. Lastly, what matters is not "giving death" but acting as consistently as possible.

Unit specificity and its effects on attitudes toward the norm

As mentioned there was no specific end-of-life law in France at the time I was conducting this study (2000-2004); the concept of an "end-of-life decision" had not been legally recognized. In April 2005, legislation was passed in France stressing patient autonomy or that of his/her legal representative. It recognized the right of doctors to withhold or withdraw therapeutic treatment when they deem the situation hopeless (French law 2005-370 of April 22, 2005 on the rights of patients at the end of life).

We can be fairly certain that the same hypothetical patient would have died in all four intensive care units studied. What would have varied from one unit to another is why, when and how the patient died. It is likely that the current law has not really affected unit specificity, though it has provided a more precise framework. The decision-making process, how much time that process takes, and the arguments mentioned in it vary from one unit to the next, as does the way of inducing death or letting the patient die, as we shall now see in greater detail.

The ways of handling ethical issues vary. We can identify at least two types of approach.

– A "legalist" approach where priority is given to respect for the law (Saint Luke's). Actors here practice "deontological" morality (Rameix, 1996) that gives primacy to the law and legality. They focus on intentions, specifically how to implement the end-of-life decision.

– An "autonomist" approach where norms may indeed be transgressed (Saint Jean's and Saint Paul's). Actors here have adopted a morality of individual and collective responsibility (the team), and priority is given to attaining the desired end. The Saint Vincent unit combines the two approaches; its culture is changing due to the new physician in charge and his different objectives.

It is worth illustrating the two approaches. The following are two examples of how the end-of-life process may be managed for the same type of patient; *i.e.*, a patient who has been resuscitated after a cardiac arrest. Once the initial treatment phase is over –once the heart has been reactivated– the main problem for the ICU team is to assess the patient's survival chances and quality of life. In many cases the brain damage caused by the cardiac arrest can only be assessed much later, sometimes too late, because the patient is in a vegetative state and no longer needs any life-support techniques. The question is what to do with such patients. Here are two different approaches, resulting from divergent local cultures.

> – Saint Luke's, Britain. A 71-year-old patient with a previous history of heart disease is admitted after a cardiorespiratory arrest. The patient had drawn up a living will in which he makes clear his wish not to be resuscitated after a cardiac arrest, but the living will is found only after the patient has been admitted into intensive care. After three days in the hospital, the patient shows no signs of improvement. The doctor in charge confides to me that if it were up to him to decide, he would suggest actively withdrawing the life-support system, but "I'm not in a position where I have the power to kill a man". The patient's children meet with the doctor for the third time and make the following request: "Couldn't you give him a huge dose of morphine, and release him for good?" The doctor's answer: "Unfortunately I don't have the right to perform that act, we're prohibited by law. The only thing we can do right now –and I know this is hard to hear– is to wait for your father to contract a lung infection which we won't treat and which he'll die of." In response to the family's request, the doctor recalled the law and opted for complete transparency, even if that meant communicating complex information that is difficult to accept. In the patient's file the indication was that it had been decided not to escalate therapy and not to prescribe any new treatment.

> Among themselves, the doctors expressed regret not to have been able to do anything to help this patient die. He remained for 10 days in the unit without any hope of recuperating –meaning he was also occupying a bed for "no good reason". Since he was not contracting any infection in the unit, the team decided to transfer him to a general ward where he stayed 12 days before dying from a untreated lung infection.

> Attitudes toward end-of-life techniques are determined by attitudes toward the law. Here the priority is to abide by the law. The doctors refuse to take any risks, even if this refusal implies a shortage of beds, a problem of consistency, and a real moral problem, as well as suffering for staff and relatives. The doctors deliberately avoid assuming total control over the situation, as they deem such control too dangerous over the long term both professionally and for matters of personal conscience and experience. The rule tends to be to let things continue as they are, and the process is thus considerably lengthened. But this atti-

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tude also allows for total transparency with regard to the families and freedom from moral guilt, which is often quite present elsewhere.

– France. [12] A 45-year-old patient is hospitalized in intensive care for cardiac arrest caused by breathing toxic fumes when a fire broke out in the hotel he was staying in. The patient's neurological state is worrying and his breathing is unstable. The patient's sister, an American doctor, says he should no longer be fed in any way –a current practice in America but not in France– but the doctors refuse to do this. A conflict develops with the sister. After six days in the hospital, the patient shows no sign of improvement. The doctors are very pessimistic and decide informally that the patient should die, but the conflict with the family prevents them from implementing this decision. "In any case, even if we decided to withdraw the life-support, we would tell her that his condition had worsened and he'd died. Stopping life support on these patients is too violent. We lower the blinds, we inject the product and we take away the respirator –it's really very violent, it amounts to killing the patient", I was told by the registrar in charge of this patient (it will be noted that in the British unit, doctors refuse to assume responsibility for "killing" the patient, while in this unit they accept it). On his eleventh day in the hospital, the team met and decided to "stop" this patient because the situation was untenable, this was "torture", and they had to "free up the bed". The registrar in charge went into the patient's room, lowered the blinds, and after a last check of patient's reactivity, he injected a massive dose of anesthetic, then withdrew the respirator. The patient died in less than ten minutes. In the medical file, it was noted that the patient had died of a lung infection that had taken a turn for the worse and that the staff had chosen not to treat any longer. The same information was given to the patient's family. Here the family impacted on the decision-making process in that the conflict between the doctors and the patient's sister delayed the move to implement a decision that had actually been made quite early on. This was "negative" impact in the sense that it did not lead to recognizing the sister as a decision-making actor and gave rise to a substantial lie.

These two examples show how variable the length of the decision-making process and the dying process itself can be from one unit to another, and how variable the prevailing type of death can be, as well the quality of the information families receive. These differences also have a major impact on the team's experience, its attitude toward the outside, and the way it communicates with patient's relatives. [13]

The timing of the dying process depends on the local approach to ethics; it depends on the unit's culture. In units where priority is given to slow dying, as in Saint Luke's, doctors sometimes feel they are making patients and their relatives suffer and are not always acting in ways that facilitate smooth unit operation. Fear of legal proceedings if the norm is not followed create a period of indecision but also a kind of implicit decision-making, what is called the "one-way ticket", the idea being to transfer the patient out of the unit –a transfer that amounts to an end-of-life decision– so as not to have to handle her death. Three arguments are cited to justify this refusal of "active" end-of-life: a justification in medical terms based on uncertainty (what if the patient's condition improved?), a justification in legal terms referring to what is prohibited; and a moral justification based on intention to "kill". Priority here is given to the law but also the means: the means of ending a person's life

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(12) To ensure total anonymity, I have not given even the fictitious name of the unit in question here.

(13) This refers to a certain type of patient only, a patient who has suffered a cardiorespiratory arrest and displays major neurological disorders.

counts more than the end of life itself –on this point Saint Vincent's also fits this model. Rather than artificially accelerating death, the doctor, either sure or unsure of her prognosis, prefers the slow process, a "law of nature" that respects the end inscribed in living beings. And this is indeed the reasoning followed: you have to let nature take its course: "We cannot play God."

In units such as Saint Jean's and Saint Paul's, where priority is *occasionally* given to quicker death resulting from a medical act, doctors feel they really are *killing* the patient and that they are being dishonest with relatives. Still, two arguments are put forward to justify this technique: patient's dignity, and the desire to shorten the family's painful wait. To these arguments is added the necessary management of intensive care beds. The objective –here, patient's death– becomes uppermost. Despite the difficulties or risks, doctors insist on enacting decisions that seem to them fair and necessary. Responsibility is at the heart of their discourse. Helping a person die, even if doing so is illegal, is presented as the doctor's responsibility as a compassionate person, as a professional conscious of suffering or the futility of therapeutic treatment, but also as regulator of intensive care unit bed availability. In this sense, the intensive care physician is being endowed with a new role: managing death in such a way as to avoid social disorganization. One doctor I spoke to put forward all three arguments: "We can't have 24 decerebrated cardiac arrest patients in our beds –we can't have that. First, no nurses would come to work here, they would all leave. Second, it would not correspond to our structure, and third, we would no longer be serving people, the patients themselves, and we wouldn't be serving their families. [...] That's our responsibility too, all that. I mean it's part of the decision, it's part of what underlies the decision." (medical professor). What emerges here is the idea of need –the need to produce death in intensive care. This is worth reflecting on. The head of this unit also said: "I find everything in these decisions really hard. It's just never simple. It's not our job, it's a new job. Our job is preserving life, and when it becomes giving death, that's a real problem. We weren't trained to do that, we haven't thought about it enough, we learn on the job."

Medically assisted dying depends on strong ICU cultures. Those cultures affect the timing and length of the decision-making process, how the decision is justified, and the way it is enacted. A serious pathology is always what ends life, but that end is also the focus of a negotiation, a social construction by professionals who are defending a considerable degree of autonomy. The existence of a legal framework never spares the actors the ordeal of the particular case, and each patient is a particular case. Doctors and nurses cannot avoid socially and morally assessing the situation they intervene in. Death is therefore more or less slow, and more or less violent, as a function of the orientations of the team caring for the patient.

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Death in intensive care units is subject to organizational constraints; it is dependent on a strong professional culture and on highly variable unit cultures. End-of-life in intensive care units is also more complex than what is reflected by outside debates. Indeed, the difficulty of making these decisions has to do with the fact that the ethical principles everyone agrees on are insufficient to enable the decision to be made. For this is indeed a matter of deciding –deciding why, when and how death will occur. Limiting a treatment, withdrawing a therapy, prescribing certain drugs, deciding on doses –all this partakes in producing death. Technological developments have made this decision-making necessary and compulsory.

The study of various ICUs brings to light a professional culture based on autonomy and self-regulation, the maintaining of borders between lay and professional worlds. While hospitals as an institution are in decline today (Dubet, 2002), intensive care is still a virtually sacred world in which the experience of all actors –professionals, patients, their families– is extreme. The classic institutional matrix remains strong in the sense that the type of social relation sought and the way of working "on others" correspond to what is disappearing elsewhere.

Autonomy and self-regulation bolster intensive care units' local cultures, and these in turn affect how dying is organized: oral *vs.* written practices; a refusal to follow legislation; in some cases, norm transgression. The decision-making process is characterized by exclusion of outside third parties (ethics committees and palliative care specialists) and by keeping patients' families at a distance. Even though relatives are increasingly likely to be present in intensive care units, they often do not play an active role around the patient and are not at the heart of discussions about his future or possible death. The family is present, but often relegated to the rank of victim, even that of patient itself; it thus loses its margin of maneuver and action. Death remains a medical decision; how it is constructed is decided by a body of experts, an elite incarnated by those experts. This means that while death practices are more transparent than before, they are still surrounded by a certain secrecy, secrecy decided by the professionals. The only information that gets revealed is what the professionals want to reveal. Death in intensive care units remains somewhere between secrecy and transparency. The medical profession wants to control how it occurs, and it has assumed for itself the production of death.

In the eyes of laypersons, this kind of death is not very clear. While they mention withholding treatment, this often gives way to images of a natural process, an inevitable death that has followed its course and is impossible to overcome. It is sometimes difficult to determine the boundary between doctors who offer relief by assuming the risk, and those who know they are in the process of accelerating someone's death. The details are never given to the relatives. Indeed, it is the barely perceptible but decisive slippage from one to the other that is the focus of debate today.

Intensive care teams have thus taken on for themselves the role of regulating death in the hospital. Managing hospital bed availability, creating a

death that will be as peaceful as possible –for the team, the patient, or the relatives– and maintaining a certain sacred secrecy are all part of this process. Medical teams accept the role of end-of-life experts, a kind of local "expertise" that has to be protected from all external intrusion. At the core of this discourse is responsibility –responsibility that is also used as a means of self-defense against the current multiplication of recommendations and norms.

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REFERENCES

Ad Hoc Committee of Harvard Medical School, 1968. – "A Definition of Irreversible Coma. Report of the Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death", *JAMA*, 205, pp. 337-340.

Bayertz K., 1992. – "Techno-Thanatology: Moral Consequences of Introducing Brain Criteria for Death", *Journal of Medecine and Philosophy*, 7, pp. 407-417.

Castra M., 2003. – *Bien mourir. Sociologie des soins palliatifs*, Paris, Presses Universitaires de France.

Christakis N., 1999. – *Death Foretold: Prophecy and Prognosis in Medical Care*, Chicago, The University of Chicago Press.

Dejours C., 1999. – *Souffrance en France. La banalisation de l'injustice sociale*, Paris, Le Seuil.

Dubet F., 1994. – *Sociologie de l'expérience*, Paris, Le Seuil.

— 2002. – *Le déclin de l'institution*, Paris, Le Seuil.

Freidson E., 1984. – *La profession médicale*, Paris, Payot.

Gisquet E., 2004. – *Les processus décisionnels en contexte de choix dramatique. Étude des décisions d'arrêt de vie dans les services de réanimation néonatale*, Thèse de doctorat en sociologie, Paris, Institut d'Études Politiques.

Glaser B., Strauss A., 1965. – *Awareness of Dying*, New York, Aldine Publishing Company.

Habermas J., 1992. – *De l'éthique de la discussion*, Paris, Le Cerf.

Hervé C. (ed.), 1997. – *Éthique médicale ou bioéthique?* Paris, L'Harmattan.

Hughes E. C., 1971. – *Sociological Eye: Selected Papers*, Chicago, Aldine-Atherton.

Kentish-Barnes N., 2005. – *Mourir à l'heure du médecin. Décisions de fin de vie et expériences des acteurs en réanimation*, Thèse de doctorat en sociologie, Bordeaux, Université Bordeaux 2.

Lemaire F. (ed.), 2003. – *Problèmes éthiques en réanimation*, Paris, Masson.

Paillet A., 1997. – "Éthique et pratiques quotidiennes à l'hôpital", *MiRe Info*, 40, pp. 22-24.

— 2007. – *Sauver la vie, donner la mort*, Paris, La Dispute.

Parsons T., 1955. – *Éléments pour une sociologie de l'action*, Paris, Plon.

Peneff J., 1992. – *L'hôpital en urgences*, Paris, Métaillé.

— 2000. – *Les malades des urgences, une forme de consommation médicale*, Paris, Métaillé.

Pochard F., Zittoun R., Hervé C., 1999. – "Controverses éthiques concernant les décisions d'abstention et d'arrêt des thérapeutiques en réanimation", *Réanimation Urgences*, 8, pp. 79-84.

Pouchelle M.-C., 2003. – *L'hôpital corps et âme. Essais d'anthropologie hospitalière*, Paris, Seli Arslan.

Rameix S., 1996. – *Fondements philosophiques de l'éthique médicale*, Paris, Ellipses.

Ricoeur P., 1990. – *Soi-même comme un autre*, Paris, Le Seuil.

Society of Critical Care Medicine Ethics Committee, 1992. – "Attitudes of Critical Care Medicine Professionals Concerning Forgoing Life-Sustaining Treatments", *Critical Care Medicine*, 30, pp. 320-326.

Strauss A., Glaser B., 1970. – "Patterns of Dying" in **O. Brim, H. Freeman, S. Levine, N. Scotch** (eds.), *The Dying Patient*, New York, Russell Sage Foundation.

Sudnow D., 1967. – *Passing On: The Social Organization of Dying*, Prentice-Hall, Englewood Cliffs.

Thomas L.-V., 1975. – *Anthropologie de la mort*, Paris, Payot.

Touraine A., Khosrokhavar F., 2000. – *La recherche de soi. Dialogue sur le sujet*, Paris, Fayard.

Vega A., 2000. – *Une ethnologue à l'hôpital*, Paris, Éditions des Archives Contemporaines.

Weber M., 1959. – *Le savant et le politique*, Paris, Plon.